

SELF-STIGMA, LONELINESS AND CULTURE AMONG OLDER ADULTS WITH MENTAL ILLNESS RESIDING IN NURSING HOMES

Vasiliki Tzouvara

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by

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ABSTRACT

This study aimed to investigate the inter-relationships between self-stigma, loneliness, and culture among older adults with mental illness residing in nursing homes. This study also explored how this population experiences self-stigma and loneliness within the context of their cultural backgrounds. A mixed-methods approach was utilised. The first phase involved a quantitative face-to-face questionnaire survey (n=16). More than half of the study participants reported low levels of self-stigma (56.3%), yet a substantial number of them scored high on the self-stigma scale (43.8%). The analysis identified a statistical relationship between stereotype endorsement and marital status (sig. =.010). No relationship was identified between Internalised Stigma of Mental illness constructs (ISMI) and age, gender, religiousness, and educational level. Loneliness was identified to be prevalent among more than half of the sample (68.8%). There was also a positive correlation between loneliness, age (sig.=.062) and religiosity (sig.=.044). The second phase involved a qualitative hermeneutic phenomenological approach involving one-to-one semi-structured interviews (n=10). Seven themes emerged: ‘social loneliness’, ‘emotional loneliness’, ‘emotional reactions’, ‘coping mechanisms’, ‘insight into illness’, ‘understanding and view towards mental illness’, and ‘behavioural reactions’. Overall, the qualitative findings supported the quantitative results but also revealed additional theoretical and conceptual insight. Most participants were collectivistic-oriented, and most experienced both social and emotional loneliness. The degree of insight into mental illness played a key role in how self-stigma was experienced, while gender and culture were found to influence how loneliness was experienced. Based on the results of both phases, a new theoretical framework is posited that explains the relationships between the concepts of loneliness and self-stigma among this population. The study also evidences and discusses a wide range of methodological issues associated with the successful recruitment of nursing homes in older adult research.

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List of abbreviations

ABS	Aggressive Behaviour Scale
AHS	Anhedonia Scale
CPS	Cognitive Performance Scale
CSCI	Commission for Social Care Inspection
DRS	Depression Rating Scale
EAC	Elderly Accommodation Counsel
ELSA	English Longitudinal Study of Ageing
EM	Expectation-maximisation algorithm
GHQ	General Health Questionnaire
GP	General Practitioner
HC	Horizontal Collectivism
HIC	Horizontal Individualism Collectivism
HI	Horizontal Individualism
HVIC	Horizontal/Vertical Individualism Collectivism
I/C	Individualism/Collectivism
IPA	Interpretive Phenomenological Analysis
interRai-LTCF	interRai-Long Term Care Facilities screening tool
ISMI	Internalised Stigma of Mental Illness

ONS	Office for National Statistics
SAMHSA	Substance Abuse and Mental Health Services Administration
SHARE	The Survey of Health, Ageing and Retirement in Europe
SWEOLD	The Swedish Panel Study of Living Conditions of the Oldest Old
VC	Vertical Collectivism
VIC	Vertical Individualism Collectivism
VI	Vertical Individualism
UCLA	University of California Los Angeles Loneliness scale
WHO	World Health Organisation

Overview of chapters

This thesis includes 11 chapters. The first chapter discusses my personal interest on the topic, outlines the aims and objectives of the two studies, and provides key background information.

Chapter 2 discusses the historical development of stigma and also reviews relevant theoretical and conceptual frameworks, including an explanation of why socio-cognitive model of self-stigma is adopted. Furthermore, the chapter critically evaluates current mental illness self-stigma literature.

Chapter 3 discusses the concept of loneliness, presents the various theoretical approaches to loneliness, and highlights the influential role of Weiss's theoretical model in this study. The chapter discusses other concepts closely related to loneliness, and critically evaluates current loneliness research literature, including evidence associated with prevalence, how loneliness is experienced, and how specific factors increase loneliness among older adults.

Chapter 4 discusses the concept of culture and provides an evaluation of the different aspects of it (culture). The chapter also describes the individualism-collectivism cultural paradigm, and the way the former paradigm has advanced our knowledge on the cultural variations between and within societies. The chapter also provides a critical evaluation of the paradigm, while it concludes with a rationale of adapting the HVIC dimensions in this study.

Chapter 5 discusses how cultural orientations influence levels and experiences of self-stigma and loneliness. The chapter aims at providing a thoroughly review on cross-cultural and within-cultural literature on self-stigma and loneliness. The latter is of significant meaning for this study since one of its primary aims is to identify the potential inter-relationships between self-stigma, loneliness and cultural orientations.

Chapter 6 discusses the overall study design and provides a rationale for the implementation of a mixed-methods approach. The chapter also presents and discusses how a mixed-method design aligns with past literature on self-stigma and loneliness. Finally the chapter discusses the epistemological stance of the researcher.

Chapter 7 discusses the quantitative arm of this study (Phase 1). Specifically the chapter describes the aims, objectives, methods, tools and sample size of the quantitative arm, while considers some of the methodological challenges of defining, measuring, and identifying

participants. The chapter also discusses the inclusion and exclusion criteria of participants, provides the rationale of the quantitative pilot study, and discusses the valuable lessons learnt. The chapter then discusses the methodological challenges in relation to nursing homes recruitment, and introduces a new ‘multi-method’ approach. The chapter then concludes with the quantitative analysis

Chapter 8 presents and discusses the quantitative results (Phase 1). This includes a description of the recruitment rates of the nursing homes, the results of the interRai-LTCF assessments, and the response rates of eligible participants. The chapter also presents the results the descriptive and inferential results in relation to ISMI, loneliness, and cultural subscriptions. The chapter concludes with the discussion of the findings.

Chapter 9 focuses on the qualitative arm of this study (Phase 2). It provides a rationale for the utilisation of a hermeneutic phenomenological approach, and describes how this approach aligns with this study’s theoretical and epistemological underpinnings. The chapter also discusses why the interactionistic model of loneliness was adopted. It also presents the aims and objectives, interview schedule, inclusion and exclusion criteria, and a discussion of the methodological challenges in relation to this phase’s sample size. The chapter then provides the rationale for the qualitative pilot study, and discusses the lessons learned from this. The chapter continues with a description of the analytical approach adopted in this phase.

Chapter 10 presents and discusses the qualitative findings (Phase 2). The chapter presents the themes and sub-themes generated in explaining experiences of loneliness and self-stigma. It also discusses differences between experiences of loneliness and self-stigma among participants, and identifies cultural variations on experiences of self-stigma and loneliness among them. The chapter concludes with the discussion of the findings, and provides a new theoretical model that synthesizes the evidence produced from this study

Chapter 11 is the concluding chapter of this thesis. It includes a discussion of the broader methodological, theoretical and clinical implications of this study, presents a critical evaluation of the study’s strengths and weaknesses, describes relevant recommendations, and presents suggestions for future research that can build on the present.

Chapter 1 Introduction to the study

1.1 My personal interest on mental illness stigma

It was back in 2003 when I first started being interested in the aetiology and consequences of mental illness upon peoples' lives. My personal interest on mental illness was quickly growing, and several years later I decided to work in the Psychiatric Hospital of Athens. The daily communication and interaction with people with mental illness motivated me to learn more about these parameters of social reality. Questions such as what the quality of life of the mentally ill is like, how they cope with the effects of the illness, and what society in general and public health practitioners in particular can do to eliminate the effects of the illness started concerning me. It was only few years later when I realised that the way people view and perceive their condition is equally important to the effects of the condition itself. It was then that a new and more fascinating path unfolded for me. I could not stop wondering how negative perceptions that people with mental illness attach to their condition might impact upon their identity and their lives. I also reflected on what types of factors might play a role in influencing how such people perceive their condition and themselves

My own personal, and socio-demographic and cultural background also impacted upon my motivation towards understanding these themes. I come from a collectivist country and have grown up in a family that subscribed to collectivist values. However I now live my life in a very different cultural environment, one that largely subscribes to individualistic values. My experiences of living in both of these types of macro-cultures and my reflections on these differences influenced my interest about how cultural variations may impact upon perceptions of mental illness. The different perceptions people hold about mental illness between my native country (Greece), and my current environment (England) were apparent from the beginning. People view, perceive and conceptualise mental illness differently in England from Greece (and vice versa), and I think this can be attributed to the different cultural values existing between and within the two countries.

My interest in this topic area has been realised through this study which has enabled me to explore and examine perceptions of mental illness, attitudes and experiences, and how these inter-relate with loneliness and cultural values. I have conducted this study among older adults with mental health problems residing in nursing homes. This age group is significant to me for two reasons. Firstly I grew up with three grandparents who are currently 80 years old.

I saw them growing older, and now constantly facing and fighting with different types of age related health problems, both physically and mentally. The way my grandparents experience their life changes motivated me to explore the needs of this age group. Secondly ‘being older’ is a process that almost all of us one day might experience. Some of us either because of the aging process or simply because of our choice may end up to reside in long term care facilities, such as nursing homes. By examining the needs of this group we might therefore be in a better future position to effectively redefine the culture of long term care facilities, and to implement effective policies and strategies in improving them.

1.2 Background

In 2015a, the UK’s Department of Work and Pensions stated that “the structure of UK’s society is changing”. This refers to the growing number of older adults (60+ years) which inevitably changes the structure of UK’s society, since for the first time older adults outnumber people under the age of 18 (AgeUK, 2015a). According to the AgeUK (2015a) there are an estimated 14.9 million people aged 60 years and above, 11.4 million people aged 65 years old and above, and 3 million people aged 85 years old and above, in the UK. The DH recognising the potential health and social consequences of the rapidly growing number of the old adult population launched a number of policies and legislations (for example, *The National service framework: older people, 2001*, *The Care Act 2014*, *Improving opportunities for older people, 2014*) with the aim of improving older adults lives by providing equal opportunities and reducing health and social care inequalities.

The demand for long-term care facilities such as nursing homes and residential care homes increases, as the number of older adults increases “disproportionally to other age groups” (Syed Elias *et al.*, 2015, p. 1). According to AgeUK (2015a) the number of older adults residing in such facilities now amounts to approximately 432,000 people. Understanding the health needs of this population therefore continues to be of significant public health importance (Garcia *et al.*, 2014).

A report from the Health and Social Care Information Centre (2013) reported that almost 30,000 older adults residing in nursing homes in England suffer from dementia or a type of mental illness. These conditions are compounded by the stigma attached to them. Self-stigma (or internalised stigma), a central focus of this study, refers to the internalisation of the public’s negative attitudes towards mental illness (Corrigan & Watson, 2002). Previous

research reveals that the prevalence of self-stigma in people with mental illness varies between 22% and 40% across age groups (Sarisoy *et al.*, 2013). This highlights that mental illness self-stigma is a major and significant problem among people with mental illnesses. However little is known about levels of self-stigma among older adults in UK-based nursing homes with the majority of self-stigma research to be implemented among outpatient older adults, and outside of the UK context. This study, therefore, attempts to address this evidence gap. That is, to examine levels and experiences of self-stigma among older adults with mental health problems in nursing homes.

Self-stigmatisation in people with mental illness has been found to associate with reduced empowerment (Lanfredi *et al.*, 2015) and quality of life (Lysaker *et al.*, 2007; Valiente *et al.*, 2015), increased severity of symptoms (Mak & Wu, 2006) and early hospitalisation (Sarisoy *et al.*, 2013). It also negatively associates with self-esteem (Rodrigues *et al.*, 2013) and self-efficacy (Kleim *et al.*, 2008), and positively correlates with social avoidance and isolation (Sarisoy *et al.*, 2013). The evidence from these studies therefore highlights the negative impact that self-stigma can have upon the lives of people with mental illness, including its negative effect on forming social relationships, participating in social life, and increasing the risk of experiencing loneliness. This is demonstrated by Świtaj *et al.*, (2014) who identified a significant relationship between loneliness and self-stigma among 110 participants with depression. What is important, though, is that loneliness remained significant when both variables (self-stigma and loneliness) were included to the regression analysis. Overall, however, very few studies examined the potential inter-relationship between loneliness and self-stigma to date. The implementation of this study aims to add to this body of knowledge.

Loneliness has been characterised as a universal feeling (Karnick, 2005) that occurs because of the deficiencies in one's intimacy and social relationships both in quantity and quality (de Jong Glerfeld, 1998). Windle *et al.*, (2011) argue that about 5% to 15% of UK-based older adults residing in the community experience loneliness, with the prevalence rate to tremendously increase among older adults residing in nursing homes (56%) (Drageset *et al.*, 2011). Loneliness has been identified as a risk factor for a number of health problems including poor cognitive impairment (Cacciopo & Cacciopo, 2013), depressive symptom severity (Singh & Misra, 2009), psychological morbidity (Victor *et al.*, 2005) and increased rates of mortality (Luo *et al.*, 2012). The literature also indicates that socio-demographic characteristics such as age (Hazer & Boylu, 2010), gender (Golden *et al.*, 2009), marital status (Bennett & Victor, 2012), living arrangements (Victor *et al.*, 2002), and social

networks (Beal, 2006) are phenomena that influence experiences of loneliness among older adults. While loneliness has attracted much research attention our knowledge remains limited with regards to its prevalence and lived experience among older adults residing in nursing homes. This study aims to provide more evidence regarding the latter population.

Loneliness and self-stigma are both considered to be socially and culturally constructed phenomena (Rao *et al.*, 2007; Alma *et al.*, 2011), that vary from one cultural context to the next (Cheon & Chiao, 2012; de Jong Gierveld 2015). Alma *et al.*, (2011) argue that culture is an important component that influences feelings of loneliness while Nilsson *et al.*, (2006) argues that "...the phenomenon of loneliness, regardless of victims' age, has become almost epidemic...cultural background plays a significant role in studies of loneliness (p. 94)". In relation to stigma, Rao *et al.*, (2007) argue that "diagnoses of mental illness are provided based on socio-cultural and behavioural norms, consequently stigma attached to mental illness is deeply tied to culture, and accordingly mental illness stigma is likely to vary across cultures (p. 1020)". Cultural variations at the individual level may also relate to impact on how loneliness and self-stigma manifests and is experienced. One key model that has been widely used in explaining psychosocial phenomena and identifying variations on attitudes, behaviours, and values across and within cultures (Okoro *et al.*, 2008) is the 'individualism-collectivism' cultural model. Its use as means of both explaining within-cultural levels of self-stigma and loneliness has not previously been attempted.

Individualistic cultural values refer to one's preference for independency and autonomy, while the collectivistic cultural values refer to one's preference for interdependency and connectedness (Triandis, 1989; Scott *et al.*, 2004). Triandis (1996) argues that cultures are not static over time, but changeable and complex. To explain this complexity he developed the four dimensional cultural model, 'horizontal-vertical individualism and collectivism' (HVIC) (section 4.2.3). These dimensions are adopted in this study and used as an explanatory model of loneliness and self-stigma.

Cross- and within-cultural evidence on mental illness stigma provides indications that people from collectivistic-oriented countries may be more likely to self-stigmatise (Abdullah & Brown, 2011; Papadopoulos *et al.*, 2013). It is worth mentioning here that our knowledge on cross cultural stigma variations comes mainly from studies among Asian Americans and African Americans (Abdullah & Brown, 2011), because most research on self-stigma has been implemented in the US (Vogel *et al.*, 2013). There is therefore a need to examine

variations on mental illness self-stigma among other cultural groups and countries. Also little is known with regard to within-cultural variations of self-stigma among older adults with mental illness residing in nursing homes. This study attempts to address these evidence-gaps.

In relation to loneliness, cross-cultural studies indicate that collectivistic oriented older adults are likely to be lonelier than their individualistic-oriented counterparts (Dykstra, 2009; Fokkema *et al.*, 2012; Lykes & Kemmelmeier, 2014). Rokach *et al.*, (2004) poignantly states “...if we accept the premise that loneliness are expressive of the individual’s relationships to the community, then it is conceivable that the difference between cultures and the ways people’s social relations are organised within them, will result in cross-cultural variations in the way people view, experience and cope with loneliness (p. 124).” Although the empirical evidence that give weight to these theoretical propositions, there is a need for evidence and further theoretical understanding of within-cultural variations of loneliness.

1.3 Aims, objectives and research questions

Phase 1: Quantitative study

Research Question:

- What are the inter-relationships between self-stigma, loneliness and individualism-collectivism among UK-based older adults with mental illness residing in nursing homes?

Aim:

- To examine the inter-relationships between self-stigma, loneliness, and cultural values among older adults with mental illness residing in nursing homes.

Objectives:

- To assess the prevalence of self-stigma and loneliness among mentally ill older adults in nursing homes, including whether and how prevalence varies within the individual level of cultural values.
- To examine whether and how socio-demographic background factors help to explain self-stigma and loneliness prevalence.
- To examine whether and how the individualism-collectivism paradigm helps to explain within-cultural self-stigma and loneliness.
- To examine the conceptual relationship between self-stigma and loneliness.

Phase 2: Qualitative study

Research Question:

- How do older adults with mental illness experience self-stigma and loneliness under the context of their cultural values?

Aim:

- To explore older adults' experiences of self-stigma and loneliness within the context of their cultural values.

Objectives:

- To explore how older adults in nursing homes experience loneliness.
- To explore how older adults with mental illness residing in nursing homes experience self-stigmatisation.
- To explore how cultural values are related to experiences of loneliness among older adults with mental illness residing in nursing homes.
- To explore how cultural values are related to experiences of self-stigmatisation among older adults with mental illness residing in nursing homes.

Chapter 2 Self-stigma: a literature review

2.1 Introduction

Before discussing the harmful effects of stigma, it is important to understand how stigma operates, in particular the concept of ‘self-stigma’ which is of key importance to the current study. In doing so, we need to first understand what stigma means, and how it has been conceptualised over time. Therefore, in this chapter, the history of stigma and an examination of how the concept has been shaped over time is provided. This includes a focus on the definitions of stigma and self-stigma and its theoretical and conceptual frameworks. This chapter also discusses and explains why the socio-cognitive self-stigma theoretical model has been adopted. Empirical evidence related to levels and experiences of self-stigma among different age groups, including older adults, are presented, as well as a discussion of the conceptual relationships between self-stigma and a range of other phenomena including self-esteem, self-efficacy, help-seeking behaviours, and treatment adherence.

2.2 History of stigma towards mental illness

The term ‘stigma’ is rooted in Ancient Greece. In ancient Greece stigma was a mark or brand burned or cut into the flesh of people who were criminals or slaves (Fisher, 2002). This mark served two main purposes: a) to distinguish the slaves and criminals from the rest of the citizens and, b) to indicate that these individuals were less valued members of society (Horti, 2007). While Greeks did not utilize the term ‘stigma’ specifically in relation to mental illness, during the Homeric age, dramas and comedies such as *the Ajax of Sophocles* and *The Madness of Hercules of Euripides* related manifestations of mental illness to shame, humiliation and loss of face (Arboleda-Flórez, 2008; Arboleda-Flórez & Stuart, 2012). Thus the idea of mental illness stigma is evidenced to exist in ancient times.

In the Christian world, and under the influence of a more religious context, the term ‘stigmata’ indicated the marks on the bodies (usually on the palms and soles) of holy persons. These marks were perceived to be similar to the marks of the crucified Jesus, and demonstrated the devotion and the sanctity of the bearer (Weiss *et al.*, 2006). Although in the beginning the term encompassed a positive meaning, these theological notions may have led to the perception during the Middle Ages that people with mental illness were possessed by devil spirits, with symptoms being viewed as manifestations of their malice (Corrigan *et al.*,

2011) which often resulted in demonstrations of ‘treatment’ such as exorcisms and executions.

There is much evidence of stigmatisation being dominant across different religions and cultures through history. Consequently, mental illness stigma as a socially and culturally constructed phenomenon dates back to the classic era and has since continued emerging.

In the 20th century, the term ‘stigma’ was resurrected by the sociologist Erving Goffman (1968) in his seminal work *‘Stigma: Notes on the Management of Spoiled Identity’*. However, it was only during the 1990s that the concepts of ‘self-stigma’ or ‘internalised stigma’ began to attract more attention (Paterson *et al.*, 2008). In the aftermath of Goffman’s book many scholars from various disciplines such as sociologists, social psychologists, anthropologists, and so forth, began to examine stigma and its concept more extensively.

2.3 What is mental illness stigma

Mental illness stigma has been conceptualised and defined by a number of scholars many of whom have been directly influenced by Goffman’s work. According to Goffman (1968) stigma is “as an attribute deeply discrediting”, while an individual who is stigmatised is diminished “from a whole and usual person to a tainted, discounted one (p. 13)”. Therefore, stigmatised individuals are perceived as different from the whole, and become unwanted because of their ‘differences’. He also proposes that social interactions cause stigma to arise. For example, when the social identity of an individual does not concur with society’s normative expectations in relation to a specific possessed attribute, then stigma occurs (Kurzban & Leary, 2001). There is, therefore, a key inter-relationship between society’s expectations and one’s social identity. Differentiations in social identity from what it is perceived as ‘normal’ may limit opportunities for social interaction, and thus social integration. The ability to become socially integrated, therefore, depends on and is being determined from society’s expectations in relation to one’s social identity. Consequently social interaction and social context are key components in explaining the process of stigma.

Jones *et al.*, (1984) argued that stigma is a socially prescribed “mark” that highlights a deviant condition which stigmatises the identity of an individual as spoiled and flawed. The personality of an individual who possesses the mark is therefore disregarded and one’s social interactions are solely formulated based on one’s deviant condition. This inevitably results to stigmatisation. Crocker *et al.*’s (1998) defines stigma as a person’s socially constructed

identity that defines whether the individual belongs to a specific social group or is devalued because of his/her attribute. One's social environment is key in determining whether a characteristic and/or attribute is devalued, and therefore stigmatised. Both definitions highlight the key role of one's social identity in relation to a specific 'mark' or attribute. They are also both useful in understanding the concept of mental illness stigma. However, they both fail to address the viewpoints of the stigmatised individuals.

Corrigan and Watson (2002) argued that mental illness stigma can be distinguished into two categories: 'public stigma' and 'self-stigma'. Public stigma is the negative beliefs that the general public holds toward people with mental health problems, while self-stigma is the internalisation of these negative attitudes (public stigma) (Corrigan & Kleinlein, 2005). Both public and self-stigma are then explained through stereotypes, prejudice, and discrimination (see figure 1). The distinction of mental illness stigma into public and self-stigma is important because as Hayward and Bright (1997) states "if there is a stigma against the mentally ill, its most significant effects will presumably be observed in those who suffer from mental illness (p. 349)". One therefore crucial element for the occurrence of self-stigma is the existence of public stigma. Therefore it can be viewed that these two concepts are inter-linked tightly bound.

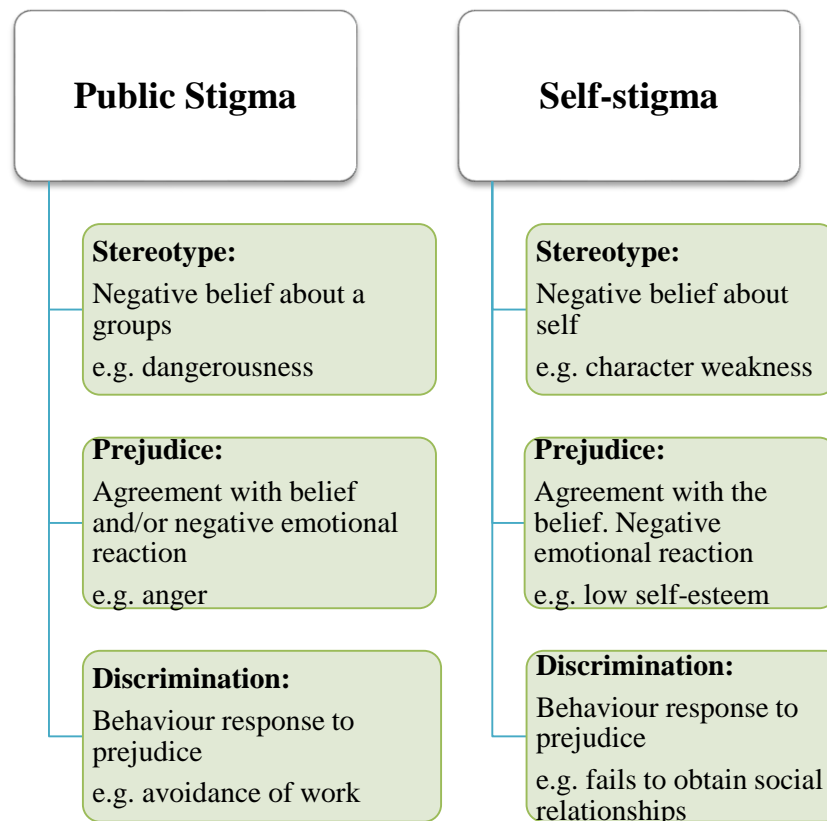


Figure 1: The conceptual distinction of public stigma and self-stigma (Corrigan & Watson, 2002)

Livingston and Boyd (2010) define self-stigma “as a subjective process, embedded within a socio-cultural context, which may be characterised by negative feelings (about self), ... which resulting from an individual’s experiences, perceptions, or anticipation of negative social reactions on the basis of their mental illness (p. 2151)”. This highlights that self-stigma is a culturally constructed phenomenon (Corrigan *et al.*, 2010; Ciftci & Corrigan, 2013) with severe consequences.

Mental illness stigma has been defined in many various ways. ‘The diverse settings that stigma has been examined’ (Green, 2009) affects its conceptualisation. However as Link and Phelan (2001) poignantly state “because of the complexity of the stigma phenomenon, it seems wise to continue to allow variation in definition so long as investigators are clear as to what is meant by stigma when the term is used (p. 365)”. In this study therefore stigma is related to a discrediting characteristic, a ‘mark’, which reflects a deviant condition for the bearer (people experiencing mental illness). This deviant condition is influenced by the negative stereotypes, and causes the bearer’s stigmatisation, and therefore, discrimination.

The bearer who endorses the negative stereotypes becomes self-stigmatised. Therefore for the purposes of this study, self-stigma is defined as the internalisation process of the negative stereotypes that the public holds and attaches towards mental illness.

2.4 Theoretical frameworks of mental illness self-stigma

Several theoretical frameworks have been proposed to explain the phenomenon of mental illness self-stigma. Link and Phelan's (2001) sociological conceptualisation of mental illness stigma proposes that stigma arises "when elements of labelling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them (p. 377)" (see figure 2). The authors therefore suggest that *power* is a key element in producing stigma. This process diminishes one's status and results in social discrimination. The four components that compose this theoretical approach – labelling, stereotyping, separation, status loss, and discrimination - are socially constructed but individually experienced. The theoretical approach is also important towards our understanding of self-stigma. Through the process of labelling, and stereotyping people experiencing mental health problems become self-stigmatised, which results to status loss, and inevitably to self-discrimination.

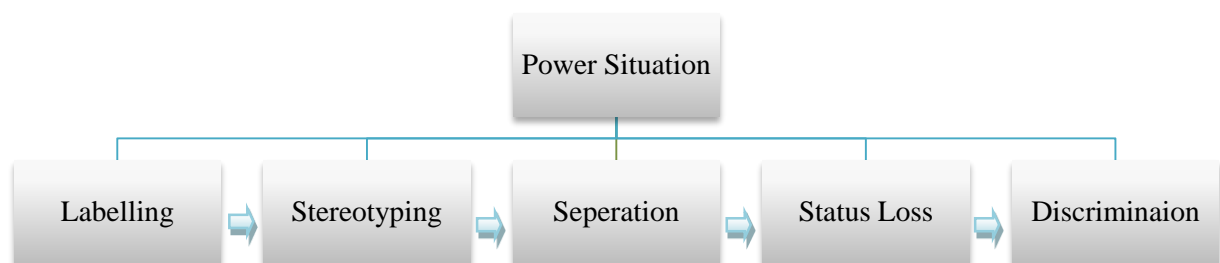


Figure 2: The self-stigma theoretical model by Link and Phelan (2001)

Three components of collective representations have been identified by Crocker (1998): a) *cultural stereotype*, b) *perceived place of the group in the social hierarchy* and, c) *socio-political ideology* (see figure 3). Cultural stereotypes are culturally constructed beliefs that influence one's behaviour and attitudes toward a specific group. Perceived place of the group in the social hierarchy refers to the beliefs that unjust social pressures such as being married, having children and being employed, result to stigmatising attitudes. People with mental health problems may be unable to meet society's pressures and become self-stigmatised by

internalising negative culturally constructed beliefs towards them. Studies provide empirical findings in relation to the role of social hierarchy, and particularly when negative attitudes are examined toward African-Americans (e.g. Philip *et al.*, 2010). However scholars are yet to accept social hierarchy as key component of mental illness stigma (Corrigan & Watson, 2002). The third component refers to views about one's social and political status. One significant agent of social and political status is work success. Individuals who are unable to obtain competitive work because of their illness are perceived as self-indulgent. Therefore, people experiencing mental health problems might endorse these perceptions and become self-stigmatised. An example to this is a study by Corrigan *et al.* (2012) among 85 people with mental health problems in Chicago area. The authors aimed to examine the associations between public and self-stigma and current and past work history. The analysis showed that there is a relationship between public and self-stigma and history of employment. More specifically, people experiencing the harmful effects of self-stigma were more likely to have been unemployed for the past 3 months, 1 year or ever. Crocker also proposes that the effect of self-stigmatisation is influenced by the individual's social and cultural contexts.

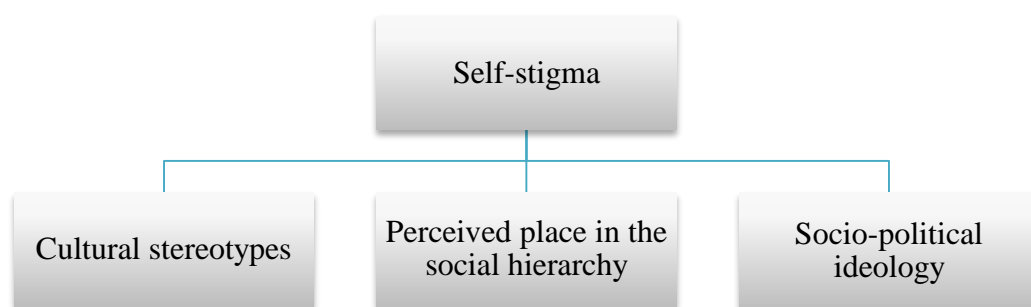


Figure 3: The theoretical-conceptual model of self-stigma by Crocker (1998)

Paterson *et al.*, (2008) propose a theoretical model that is based on five key constructs of self-stigma: *difference*, *inevitability or unchangeability*, *comparison*, *devaluation*, and, *discrimination* (figure 4). *Difference* signifies perceptions and expressions of being different from others (e.g. something is wrong with me!). *Inevitability or unchangeability* concerns beliefs that the condition is static, and therefore unchangeable. *Comparison* refers to the degree that the mentally ill compare themselves to people without a mental illness, and believe that they are less valuable (e.g. I am mentally ill, so I am less worthy than other people). *Devaluation* refers to perceptions of being less entitled than other people in finding

employment or accommodation. The last component is *discrimination* which causes feelings of social isolation, social exclusion and rejection. Paterson *et al.* state that all of the above components are interlinked with each other (not just linearly). While this model perceives discrimination as one of its main features, stereotypes are failed to be explicitly and/or implicitly used which is one of its main shortcomings. Previous models of mental illness self-stigma based their conceptualisation on culturally constructed stereotypes, with empirical evidence to give weight to these theoretical propositions (e.g. Muñoz *et al.*, 2011). However, Paterson *et al.*'s theoretical model fails to recognise stereotypes as key components of the process of self-stigma. One of the model's advantages, however, is that its conceptualisation is based on evidence coming from a group of people with mental health problems experiencing self-stigma. This is significant since it provides key information on the way people experience and think about the process of self-stigma from an 'inner perspective'. However Paterson *et al.*'s theoretical model has not yet been empirically tested which is one of the reasons why it was not adopted in the current study.

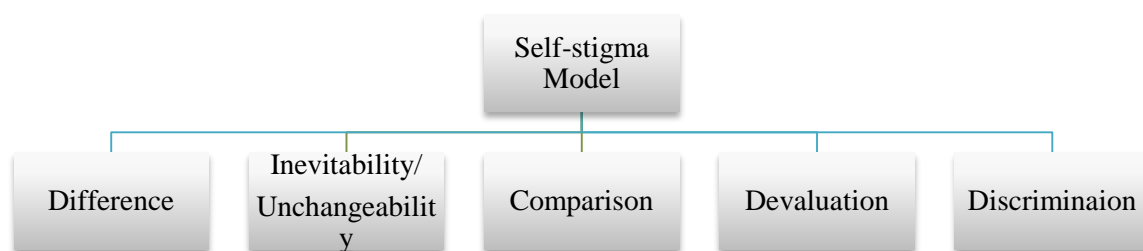


Figure 4: The theoretical self-stigma model by Paterson et al. (2008)

One significant and widely used theoretical model of self-stigma is that of the 'socio-cognitive' approach that has been advocated by Corrigan and co-authors (2002; 2005; 2011). The socio-cognitive theory was influential towards the theoretical conceptualisation of mental illness self-stigma proposed by Corrigan *et al.* According to Bandura (1989) socio-cognitive theory "favours a model of causation involving triadic reciprocal determinism. In this model of reciprocal causation, behaviour, cognition and other personal factors, and environmental influences all operate as interacting determinants that influence each other (p. 3)". In relation to mental illness, behaviour, cognition and socio-cultural and environmental contexts are key in the self-stigmatisation process. Corrigan and co-authors, based on the socio-cognitive

theory, argue that mental illness self-stigma is socially constructed through stereotyping, prejudice, and discrimination. Stereotypes are culturally and socially constructed views and beliefs toward a group of people (Rüsch *et al.*, 2005; Corrigan *et al.*, 2005). Dangerousness, blame and social incompetence are some of the harmful stereotypes that are attached to individuals experiencing mental illness health problems (Corrigan *et al.*, 2011). Individuals with mental illness are likely to be aware of such stereotypes. Prejudice occurs when people internalise stereotypes and show negative emotional reactions toward the stereotyped group. Thus, discrimination toward the stereotyped group arises when people response to prejudice (Corrigan *et al.*, 2011). For example, self-prejudice causes negative emotional reactions through the application of the negative stereotypes, and result to self-stigmatisation and self-discrimination. The Corrigan *et al.*'s socio-cognitive self-stigma model is also known as the three 'A's': awareness, agreement and application of the negative stereotypes (Corrigan *et al.*, 2009) (figure 5). Awareness about negative stereotypes does not necessarily result in internalisation. As Watson and River (2005) argue, while people with mental illness might be aware of the public's stereotypes, they might not agree, and thus not apply to themselves. The socio-cognitive model also highlights the negative effects of self-stigma upon the self-esteem and self-efficacy of people experiencing mental health problems. This may result to the 'Why to try' effect. The 'Why to try' effect explains how self-stigma may result to powerlessness (Corrigan *et al.*, 2009), and thus people's with mental health problems reluctance to retain an active role in the society. For example, they might be reluctant to pursue work and/or independent living, develop social relationships and/or become socially and emotionally integrated. Studies have evaluated Corrigan and co-authors' socio-cognitive self-stigma theoretical model and provided significant evidence supporting its effectiveness (Muñoz *et al.*, 2011; Drapalski *et al.*, 2013). The socio-cognitive theoretical model has been adopted in this study (section 2.4.1 in chapter 2 discusses why this model is adopted).



Figure 5: The adopted socio-cognitive theoretical model of self-stigma (Rao & Corrigan, 2005)

The cultural and societal influences towards explaining mental illness self-stigma process are apparent within these models and therefore a key reason why this study includes a key focus on cultural values in understanding self-stigma among older adults experiencing mental health problems in nursing homes.

2.4.1. Rationale for adapting the socio-cognitive self-stigma model

The socio-cognitive self-stigma model explains the process of self-stigma through cognitive processes that are influenced by one's cultural and social environments. A key aspect of self-stigma within this model is the negative stereotypes that exist in relation to mental illness. This is because the awareness, agreement and application of these stereotypes trigger internalised stigma to occur. This may then lead to a range of harmful consequences including self-isolation and self-discrimination which may increase the risk of loneliness.

The socio-cognitive theory refers to triadic mutual determinism causation (Bandura, 1989) in that cognition, behaviour, and other personal and environmental characteristics influence each other in determining behavioural outcomes. The self-stigma model adopted in this study is influenced by the socio-cognitive theory, and builds upon it in order to explain the process of mental illness self-stigma. Therefore, according to the socio-cognitive self-stigma model, the awareness, agreement and application of the negative stereotypes among people with mental illness is influenced by one's cognitive, personal and societal/cultural characteristics. The idea that social and cultural contexts influence self-stigma process aligns with the scope of this study, provides rationale aiming to explore the inter-relationships between cultural

values and experiences of self-stigma, and explains the key reasons why the socio-cognitive self-stigma model has been adopted.

The socio-cognitive self-stigma model has also been widely used in mental illness stigmas literature. For example, Kim *et al.* (2015) utilised the socio-cognitive self-stigma model to assess prevalence of self-stigma and to identify factors associated with self-stigma (socio-demographic, clinical, and psychosocial variables) among 160 Koreans experiencing mental health problems. Also Mashiach-Eizenberg *et al.* (2013) used both the socio-cognitive self-stigma model and the path model of self-stigma (Yanos *at al.* 2008; Yanos *et al.* 2010) in order to examine the relationships between subjective quality of life and internalised stigma, and to investigate the mediating role of hope and self-esteem among 179 Israelis with severe mental health problems.

The socio-cognitive self-stigma model has also been empirically evaluated. For example Muñoz *et al.*, (2011) aimed to examine the inter-relationships between the core variables of internalised stigma (socio-demographic and clinical variables, social stigma, psychosocial functioning, recovery expectations, empowerment, and discrimination experiences) among 108 patients with severe mental illness. The structural equation model involved a number of social, cognitive, and behavioural variables (core features of the socio-cognitive model (Rüsch *et al.*, 2005)). The authors utilised several outcome measures: the Attribution Questionnaire, the Internalised of Mental Illness Scale, the Psychosocial Functioning Scale, the Recovery Assessment Scale, the Boston University Scale to assess empowerment, and one direct discrimination experience tool that assessed participants' discrimination experiences in 11 different situations (work area, academic life, family or partner situations, health area, leisure areas, social services, transportation, housing, friends, neighbours, and other people with mental illness). Overall the results show a positive and direct correlation between internalised stigma and social stigma (fear/avoidance), and discriminating attitudes (family members, partners and friends), while internalised stigma was found to negatively affect the behavioural outcomes of the illness (autonomy/social function). The model also shows that cognitive variables (self-esteem/empowerment/recovery expectations) have a mediating role in this relation. The study reveals that cognitive, behavioural and social variables explain the process of self-stigma, and provides empirical findings that support the effectiveness of the socio-cognitive self-stigma model which has been adopted in this study.

2.5 Prevalence and experiences of mental illness self-stigma

In January 2013, the ‘Time to Change’ national anti-stigma programme in England released the findings of its survey on experiences of stigma and discrimination. Almost 5,000 people with mental health problems participated in the survey. The findings revealed that 58% of the participants believe that stigma towards mental illness is as bad as the illness itself, and 38% stated that they experienced stigmatising and discriminatory attitudes on a monthly or weekly basis. According to the official site of the Time to Change Campaign (2014) “*shockingly, one in ten people even say they face it (stigma & discrimination) every single day*”. In addition, 28% of the participants waited more than a year to disclose their illness to their family, 22% waited more than a year to talk to their GP, 44% said that stigma and discrimination has discouraged them from searching for or returning to work, while 61% of them have faced stigmatising and discriminatory attitudes from both friends and their social environments. Gerlunger *et al.*, (2013) in a systematic review examined prevalence, relationships interventions and effects of personal stigma among people experiencing schizophrenia. The authors defined personal stigma as the triadic conceptual combination of experienced stigma, perceived stigma and self-stigma. The findings showed that perceived stigma amount to 64.5% (range=45.0–80.0%), experienced stigma to 55.9% (range=22.5–96.0%), and self-stigma to 49.2% (range= 27.9–77.0%). More specifically, in relation to self-stigma 26.8% of participants reported stereotype endorsement/agreement, 49.2% alienation, and 52.6% stigma resistance. Alienation was the most commonly reported aspect of self-stigma. This evidence reveals that stigmas and discrimination experience is a present and constant challenge for people experiencing mental health problems. It is therefore quite surprising that empirical evidence of levels and experiences of internalised stigma are still limited within the UK context.

Girma *et al.* (2013) examined the prevalence of self-stigma and its correlates among a representative sample of 422 patients with mental illness living in Ethiopia. The study results showed moderate levels of self-stigma, with a small number of participants (25.1%) to score high on the self-stigma scale. More specifically, participants reported high feelings of inferiority, but less stereotype agreement. Brohan *et al.*, (2010) examined levels of self-stigma among 1229 individuals suffering from schizophrenia, psychosis or schizoaffective disorder across 14 European countries. The findings showed that almost half of the participants (41.7%) reported moderate or high levels of self-stigma, while 69.4% reported

high to moderate levels of perceived discrimination. That is, the majority of them believed that there are negative public attitudes towards people using mental health services. The authors argued that self-stigmatisation “appears to be common and sometimes severe among people with schizophrenia or other psychotic disorders in Europe” (Brohan *et al.*, 2010, p. 232).

Werner *et al.* (2008) investigated the relationships between self-esteem and self-stigma among 86 older and younger in-patients with schizophrenia (mean age=54). Overall, levels of self-stigma were moderate among participants, with less than half reporting high self-stigma levels (20-33%). In a similar study one year later Werner *et al.*, (2009) examined levels of self-stigmatisation and its relationship with self-esteem among 54 Israeli older adults experiencing depression. They found that overall levels of self-stigma were moderate among the sample of the study, with younger older adults to report higher self-stigma. High levels of self-stigma were found to correlate with low income and education.

Griffiths (2008) investigated self-stigma and willingness of treatment adherence among 14 UK-based older adults with mental illness using out-patient mental health services (age range= 65-92). The small study revealed low levels of self-stigma and found that self-stigma did not impair participants’ willingness to continue using mental health care services. However, a small number of studies investigated self-stigma among patients residing in health care facilities. In addition, there is an inconsistency in the literature about the relationship between age and levels of self-stigma. That is, a relationship of causality between old age and levels of loneliness has yet to be established. Livingston and Boyd (2010) in a systematic review and meta-analysis aimed to investigate the statistical relationships between self-stigma, socio-demographic, psychosocial (e.g. home/empowerment) and psychiatric variables (e.g. hospitalisation/symptoms severity/diagnosis) among people experiencing mental illnesses. They found that age was the most common socio-demographic variable that significantly associated with higher levels of self-stigma (31.4%). However, the direction of the relationship was neither consistent nor clear (Livingston & Boyd, 2010). More specifically, 36.4% of studies reported significant associations between high levels of self-stigma and being older, while 63.6% revealed that being younger significantly associates with higher self-stigma levels. The meta-analysis included a highly heterogeneous set of studies, including in relation to outcome measurement tools (n=127). Furthermore, only 9 out of the 45 studies included in the meta-analysis

examined self-stigma levels among mental health patients living in care facilities. The authors argued that the majority of studies utilised cross-sectional designs which is one key methodological gap in the self-stigma literature since relationships of causality between variables cannot be established.

Lanfredi *et al.*, (2015) investigated the relationships between social capital, self-stigma and empowerment among 516 people with major depressive disorder in 19 European countries. The results of the study showed low/moderate levels of self-stigma among participants. In the same line was Mosanya *et al.*'s (2014) study. They sampled 266 psychiatric outpatients with schizophrenia in Nigeria, and found that a small number of participants (18%) experience high levels of self-stigma. Yet, social withdraw and stigma resistance subscales had the highest scores. Participants therefore were more likely to avoid social interaction and communication with others. In a systematic review of the literature Boyd *et al.*, (2014) aimed to investigate and evaluate the 29-item Internalised of Mental Illness Scale (ISMI). The authors reviewed 81 studies which used the ISMI scale to assess levels of self-stigma. Almost half of the participants reported high self-stigma, with the alienation and stigma resistance subscales having the highest scores. The authors stressed out the limited number of longitudinal studies, and the need to investigate cultural effects on self-stigma.

Kim *et al.* (2015) assessed 160 inpatient and outpatient Koreans with mental health problems and investigated levels of self-stigma and its relationship with self-esteem, hopelessness, social support, and social conflict. The authors found low levels of self-stigma among this population, yet stereotype endorsement scores were high among them. Correlation analysis revealed a negative relationship between self-stigma, levels of self-esteem, length of hospitalisation and perceptions of social support. The authors argued that low levels of self-stigma among this population resulted because the majority of the participants were inpatients. "In the inpatient setting, patients are separated from the majority of social situations for the duration of their hospitalization and therefore may be less aware of their internalized stigma" (Kim *et al.*, 2015, p. 346). They also found no significant relationship between levels of self-stigma and type of mental illness. This comes in conflict with other recent studies. One such example is Karidi *et al.*'s (2015) experimental study. They sampled 60 outpatients suffering from schizophrenia, and 60 outpatients suffering from bipolar disorder in the UK. They examined levels of self-stigma, investigated differences on self-stigma levels among groups, and explored factors that affect stigma levels. The results

showed that self-stigma is present in both groups, yet participants with schizophrenia scored almost 6 times higher on the self-stigma scales compared to their bipolar disorder counterparts.

Conner *et al.*, (2015) using a mixed-methods approach investigated how peer education (PE) interventions improve attitudes and minimise self-stigma among 19 US-based older adults (60+) suffering from depression. The intervention phase was followed by semi-structured interviews to enable participants' perceptions about stigma and the PE intervention to be explored. Pre intervention analysis showed that both perceived public stigma and levels of self-stigma were moderate to high among this age group. In the same line, semi-structured interviews revealed that mental illness stigma exists in this age population. Older adults argued that their cohort age was happy to openly discuss physical problems, yet they were reluctant to discuss problems related to their mental health well-being. Also older adults hold negative attitudes towards mental health treatment, and were reluctant to talk to mental health professionals. Finally older adults believed that seeking treatment would further increase stigma experiences. The authors concluded that PE interventions can reduce levels of self-stigma among this population, and suggested that more research evaluating PE programmes through random control trials is needed.

Experience of self-stigma has also been investigated through qualitative research studies. For example, Michalak *et al.*, (2011) explored experiences of internalised stigma among 32 outpatient Canadians suffering from bipolar disorder. Their analysis revealed that all of the study participants had experienced stigma during their illness. Participants also described that their identity is negatively defined by their condition, that often their bipolar disorder had negatively affected their own self-image (although not always), and that self-stigma was a major influence towards their ability to manage their illness. A recent qualitative study reports similar findings. Ward *et al.*, (2015) explored experiences of depression and coping mechanisms among 13 African American women living in the community (60+). No explicit exploration of experiences of self-stigma was intended. However, the findings revealed that respondents were reluctant to seek treatment and admit their illness because of the stigma attached to their condition. The authors stressed the need for more culturally focused research on experiences of mental illness. It is worth mentioning that a number of qualitative studies explored experiences of stigma (for example Dinos *et al.*, 2004; Suto *et al.*, 2012), yet there is a lack of qualitative exploration of the self-stigma phenomenon.

To summarise, self-stigma is present among people experiencing mental illnesses, however studies report inconsistent findings. More specifically, levels of self-stigma vary from low to high, with most studies reporting moderate/high levels of self-stigma. The majority of the studies sampled participants from various age groups, which makes comparisons between them problematic, while fewer studies examined self-stigma levels among inpatient older adults. In addition, the qualitative exploration of experiences of self-stigma is limited and/or not explicitly explored, and there is a need for more culturally focused research on self-stigma. This study attempts to add to the current evidence base in investigating both the statistical prevalence and qualitative experience of living with self-stigma among UK-based older adults residing in inpatient facilities.

2.5.1 The relationship between self-stigma, self-esteem and self-efficacy

The relationship between self-esteem, -efficacy and self-stigma has been both theoretically (Corrigan & Watson 2002), and empirically documented (e.g. Berg & Ranney, 2005; Corrigan *et al.*, 2006; Germa *et al.*, 2013). Jones (1980) proposed that self-esteem “is the ratio of success and pretensions in important life domains” (cited in Sowislo & Orth, 2013, p. 213), while Robins *et al.* (2001) stated that self-esteem refers to the way people evaluate, perceive and feel about themselves. Corrigan and Watson (2002) argued that poor self-esteem results due to the agreement, endorsement and application of mental illness stigma towards oneself. That is, there is a relationship between self-stigma and self-esteem decrements among people experiencing mental health problems. Link *et al.*, (2001) substantiated this idea by finding that, among 70 mentally ill individuals, lower self-esteem significantly associated with higher perceptions of perceived stigma. Sultan (2011) also examined levels of self-esteem and perceived stigma among 188 individuals. One hundred of them were suffering from mental health problems, while 88 of them were suffering from diabetes. The findings showed that among those suffering from mental health problems, those who experienced higher levels of perceived stigma also presented with lower self-esteem.

Werner *et al.*, (2008) investigated the relationships between self-esteem and self-stigma among 86 older and younger inpatients experiencing schizophrenia. The findings showed that self-stigma was significantly correlated with levels of self-esteem among this age group. In their second study, Werner *et al.*, (2009) examined levels of self-stigmatisation and its relationship with self-esteem among 54 Israeli older adults experiencing depression. They also found that participants with higher levels of self-stigma reported lower levels of self-

esteem. In both studies correlations of levels of self-stigma and self-esteem were reported among older adults experiencing mental illness. Negative relationships of levels of self-stigma and self-esteem seem to be dominant among older adults with mental health problems, yet as Werner et al. (2008; 2009) argue this area of research attracted little attention.

Segalovich *et al.*, (2013) investigated the relationships between self-stigma, self-esteem and ability to maintain intimacy relationships among 60 outpatients and inpatients experiencing schizophrenia in Israel. They found that levels of self-stigma significantly correlate with self-esteem among outpatient participants. However, the findings showed no significant relationship between self-stigma and self-esteem among inpatient participants. The authors argued that inpatients go through an acute phase of schizophrenia, and therefore are more likely to have low insight into their condition. Their self-esteem therefore remains intact because they do not consider themselves coping with a psychiatric disorder. In addition, the authors argued that inpatients spent long time in hospital facilities and with peers also experiencing psychiatric disorders, and therefore they experience stigmatisation stress. Therefore their self-esteem remains unimpaired. In relation to ability of retaining intimacy relationships, the authors found that high levels of self-stigma correlated with decrease ability to maintain intimacy relationships among the outpatients group. This may result to feelings of loneliness. Rodrigues *et al.*, (2013) reported similar findings among 50 individuals (inpatients/outpatients) experiencing schizophrenia-spectrum and substance use disorders in Massachusetts. They found that self-esteem decrements related to self-stigma between both groups (both patients with schizophrenia-spectrum and substance use disorders).

Self-stigmatisation has also been found to impact negatively on the self-efficacy of the mentally ill. Self-efficacy “is the belief that one has the power to produce that effect by completing a given task or activity related to that competency” (Online Nursing Theories, 2012). Mentally ill who perceive themselves unable to function well in the society because of their condition may report lower self-efficacy. Corrigan *et al.*, (2006) examined the relationships between self-stigma, self-esteem and self-efficacy among 114 mentally ill individuals. The study findings revealed that participants whose perceptions concur with the negative beliefs toward them reported diminished self-esteem and self-efficacy. Kleim *et al.*, (2008) report similar findings. They examined levels of self-efficacy among 122 in-patients suffering from schizophrenia. The findings showed that even when age, gender, impact of depression, psychopathology and insight were controlled, perceived stigma was correlated with reduce self-efficacy and high preference for social isolation and withdrawal. The latter

is consistent with the argument of Watson and Angell (2012) that the mentally ill may prefer to retain their intimacy relationships among their family members or may prefer to be isolated (Manojlovic & Popovic, 2012) due to stigmatisation attitudes that surround their condition.

In a recent study Hill and Startup (2013) investigated how self-efficacy mediates the relationship between self-stigma, negative symptoms and social functioning among 60 in-patients experiencing schizophrenia. The findings revealed strong associations between self-stigma and self-efficacy. Lower self-efficacy associated with higher levels of self-stigma. Also there was a strong correlation between self-stigma and both negative symptoms and ability for social integration among participants. This might increase feelings of loneliness among them because of the lack of social and intimacy relationships. The authors argued that people suffering from schizophrenia consider themselves as incapable of achieving goals and performing important tasks and behaviours because of self-stigma. They argued however that there is a need for longitudinal studies so as to establish relationships of causality.

To summarise, there is a relationship between self-esteem, self-efficacy and self-stigma among people experiencing mental health problems. Higher levels of self-stigma correlated with lower levels of self-esteem and self-efficacy both among inpatient and outpatient participants. The studies also identified relationships between self-stigma, self-esteem and poor social functioning. This may result in increased levels of loneliness among people with mental health problems. However there is a limited number of studies that examined the relationships between self-stigma, self-esteem, and –efficacy specifically among the older population, and the majority of studies adopted cross-sectional study designs, and therefore no causality relationships can be determined between variables.

2.6 Self-stigma, treatment adherence and treatment engagement with mental health services

The United State's Substance Abuse and Mental Health Services Administration (SAMHSA) (2010) reported that 45.9 million people were experiencing mental health problems, yet only the 39.2% of them engaged with mental health services. Internalised stigma may explain why people with mental health problems are reluctant to seek professional help, adhere to treatment, and engage with mental health services. Fung *et al.*, (2008) in a cross-sectional study of 86 individuals with schizophrenia found that high levels of self-stigma and lower

self-esteem were two components that significantly correlated with participants' poor treatment adherence and engagement with mental health services. The authors argued that people experiencing schizophrenia discontinue treatment because they wish to conceal their illness to minimise discrimination. Vrbová *et al.*, (2014) reported similar findings. They implemented a cross-sectional study among 90 outpatients with psychotic disorders in determining the relationship between self-stigma, discontinuation of psychoactive drugs in the past, and current adherence to treatment. The analysis revealed a significant negative correlation between self-stigma and current adherence to treatment among participants. Self stigma therefore is a core feature of poor treatment adherence and engagement with mental health services among this population. Corrigan (2005) argues that individuals who internalise stigma may often experience and report feelings of hopelessness. This may help to explain why self-stigma negatively impacts upon treatment adherence as both Wade *et al.*, (2011) and Fung *et al.*, (2008) argued that experiencing hopelessness can prevent help-seeking behaviours, thus impairing recovery outcomes.

Vogel *et al.*, (2010) investigated how public stigma and self-stigma affects individuals' attitudes of seeking psychological help amongst 491 college students. They revealed that higher degrees of public and self-stigma predicted lower intentions of seeking psychological help. They argued that further examination of the way that culture and more specifically the individualism-collectivism paradigms influences self-stigmatisation, and willingness to seek professional help is needed. Jennings *et al.*, (2015) examined the relationships between self-stigma, perceived-stigma, self-reliance and seeking professional health among 246 University students. The relationships between self-stigma and help-seeking intentions were restricted among students who self-reported and were assessed positive for mental health problems. They found that high levels of self-stigma significantly correlated with reduced help-seeking behaviour. Also they found that self-reliance and self-stigma mediated the relationship between help-seeking behaviour and perceived stigma, and they proposed a three pathway model of stigma and help-seeking behaviour among people with mental health problems. The authors argued that "when individuals perceive that others would view them negatively for seeking treatment, they may endorse similar stigmatizing beliefs toward themselves, and subsequently prefer handling problems on their own rather than seek treatment (p. 113)".

The studies provide an important understanding about the relationships between self-stigma, treatment adherence, and treatment-seeking behaviours among people experiencing mental

health problems. Although the studies cannot establish cause and effect relationships, they provide useful information and grounds for further investigation on the matter.

2.6.1 Stigmas as barrier to older adults' treatment adherence and engagement with mental health services

It is consistently found that older adults are reluctant to seek psychological help and they underutilise mental health services (Rue & Sirey, 2011; Woodhead *et al.*, 2013; Garcia *et al.*, 2014; Jimenese *et al.*, 2015), despite these services importance in promoting positive outcomes.

Conner *et al.*, (2010) states that “older adults seek mental health treatment less than any other adult age group (p. 972)”. Their qualitative study of 37 older adults suffering from depression (nested within a randomised controlled trial) revealed that internalised and public stigma were key barriers of the participants' intention to seek professional treatment and to disclose their illness: *‘Nobody mentions the word psychiatrist. You know. First thing they think about is something wrong with your mind’*. This highlighted the stigma attached to psychiatry. *‘Why would anybody say that they’re going to see the shrink? I just don’t get it. If people got the blues, they keep it to themselves. I think mental depression and mental health is something that the people with whom I associate, they keep it to themselves. If they’re going to the shrink, you’re going when nobody’s looking’*. Conner *et al.* argued that this demonstrated the desire for older adults to keep their illness secret.

Zivin and Kales' (2008) narrative systematic review identified stigma as a key modifiable factor that negatively influenced willingness of treatment adherence among older adults. Sirey *et al* (2001) examined perceived discrimination and its effects on treatment discontinuation among 99 outpatients suffering from depression, 29 of whom were older adults. The study's findings indicated that perceived stigma negatively affects treatment participation among the elderly. What is more, the authors found that perceived stigma were higher among younger adults, yet treatment discontinuance was more prevalent among older adults. The authors argued that people seeking treatment face the greater effects of stigma because “they must face the reality of receiving mental health treatment (p. 480)”. This, they argued, entails loss of social relationships which for older adults might have a greater effect, and therefore directly impacts on their willingness for treatment adherence. Another study by Smith (2012) investigated the impacts of individual's perceptions of stigma, depression,

and resilience on older adults' willingness to seek treatment in a cross-sectional study. The participants were 158 community dwellers older adults 65 years old and older. The findings demonstrated a significant correlation between perceived stigma, symptoms of depression, resilience and willingness to seek treatment.

Segal *et al.*, (2005) found that the negative attitudes that older adults hold toward mental health problems and experiences of stigma due to their mental illness are two potential barriers which result in reluctance of seeking psychological help. Vogel *et al.*'s (2011) study of help-seeking behaviours, masculinity norms and self-stigmatisation among 4773 men also showed that self-stigma negatively correlated with participants' willingness to seek professional help. The authors stated that self-stigma could be considered as a main predictor of help-seeking behaviour and "may be a more proximal indicator than masculine gender role norms" (Vogel *et al.*, 2011, p. 375). That is, self-stigma might have a greater effect on help-seeking attitudes compared to masculine beliefs.

Stewart *et al.*, (2015) examined the relationships between stigmas (public stigma and self-stigma) and help-seeking attitudes among 126 older adults living in rural and urban areas in the US. The findings showed that high levels of public and self-stigma correlated with less intention for seeking psychological help among isolated rural older adults. That is, stigmas negatively impacted on mental health seeking behaviours among rural older adults. The authors argued that within-cultural beliefs could partially explain help-seeking differences among participants. Rural older adults might believe that people should be able to handle their problems, and therefore view seeking psychological help as a weakness. The authors also highlighted the need for more research on the cultural variations of mental illness stigmas.

To summarise, the literature reveals that self-stigma correlates with diminishing help-seeking behaviours and treatment adherence among older adults. The majority of the studies, however, focused on examining self-stigmatisation and its relationships with seeking professional help and treatment adherence among community-dwellers older adults. Fewer studies investigated experiences and perceptions of self-stigma in relation to attitudes of treatment adherence among mentally ill older adults residing in health care settings. This highlights the need for more research on the topic. Finally, the majority of the studies have adopted cross-sectional designs, and therefore causality cannot be established.

2.7 Summary

Stigma is rooted back in Ancient Greece. During its early conceptualisations the term was not utilised in correlation to mental illness. It took several forms before the concepts' resurrection by the sociologist Erving Goffman (1968), in the 20th century. The theoretical foundations of stigma vary, however when stigma is explicitly defined most scholars cite Goffman's definition. There are a number of definitions and theoretical models of mental illness stigma. According to them public and self-stigma is one key theoretical distinction of the concept. The latter distinction advanced the mental illness stigma literature.

In this study, the socio-cognitive self-stigma model is adopted. The model is developed by Corrigan and Watson (2002) and is based on and influenced by the socio-cognitive theory. According to the model self-stigma occurs because of the culturally and socially constructed stereotypes towards people with mental health problems. The process of self-stigma follows a cycle which begins with the awareness of the stereotypes, and ends with the application of the stereotypes to one's self. The key reason for the utilisation of the former model is because it explains self-stigma through socially and culturally socio-cognitive processes.

The literature review shows that levels and experiences of self-stigma are present among people with mental health problems, with its levels to range from high to moderate. The number of studies however is limited, which highlights the need for more work on the topic. The majority of the studies examined heterogeneous age groups, which makes comparisons problematic, while the limited number of studies particularly among older adults makes inferences unfeasible. Finally the literature reveals the small number of studies among UK-based older adults.

The literature also highlights the relationships between self-stigma, self-esteem and self-efficacy. The studies reveal that self-stigma significantly correlates with self-esteem and self-efficacy decrements among people experiencing mental health problems. Moreover studies indicate that self-stigma negatively affects willingness to seek treatment, and engage with mental health services. Finally the literature shows that mental illness stigmas (public and self-stigma) are key barriers to older adults' treatment adherence and engagement with mental health services. The majority of the studies, however, adopted cross-sectional designs, and therefore cause and effect relationships cannot be established.

Chapter 3 Loneliness: a literature review

“...although the human race is made up of different peoples, and despite the diversity of age, sex, culture language and religious beliefs, there are fundamental similarities. One of these similarities is our yearning for love, acceptance and understanding, and conversely our hedonistic nature and aversion to such painful experiences as loneliness.”
Rokach (1989, p. 382)

3.1 An introduction to loneliness

Loneliness is as an effusive, debilitating and frightening condition that affects all stages of individuals' lives. Discussions surrounding loneliness have been dated since the ancient times and have been continued to emerge until recent years. From the times of Plato and Aristotle (427-322 BC) until Tillich (1952) philosophers attempted to comprehend, define and conceptualise how individuals perceive, and cope with loneliness. In more recent years conversations about loneliness relate to individuals well-being. Loneliness is extensively used not only as an indicator of 'successful living' but also as an indicator of 'successful aging' (de Jong Glerveld, 1998). This simply witnesses the inherently connection of loneliness with the human nature (Karnick, 2005).

Loneliness has attracted much research attention. Many studies examined the prevalence and impacts of loneliness among various sections of the public. For example, studies examined loneliness among the young (Ejerskov *et al.*, 2015), the old (Taube *et al.*, 2015), and the general population (Qualter *et al.*, 2015; Wright *et al.*, 2015). Decades of research show that loneliness associates with a range of severe health problems including poor cognitive impairment (Cacciopo & Cacciopo, 2013), higher symptoms of depression (Singh & Misra, 2009), increased rates of mortality (Luo *et al.*, 2012), mental morbidity (Victor *et al.*, 2005), and poor physical health (Hawkey & Cacciappo, 2010; Tiwari, 2013; Mushtaq *et al.*, 2014; Shiovitz-Ezra, 2014).

This chapter discusses the various theoretical foundations of loneliness in order to gain a better understanding of its nature. Also, it discusses and presents the various definitions of loneliness, while discussing similar concepts of loneliness which are often used interchangeably and highlights their different nature and context. Finally this chapter

discusses the prevalence and experiences of loneliness among older adults, while presents the factors that are correlated with increasing levels of loneliness among this population.

3.2 Loneliness: definition and conceptualisation

Many authors have attempted to provide definitions of loneliness. A key explanation for the variability of the definitions of the concept is the multidimensional and subjective nature of it. Some of the definitions therefore highlight the subjective effusive and painful nature of the condition, while others explain the concept through an objective and more disconnected way. In table 1, ten distinct definitions of loneliness are described, each of them highlighting different components of the condition.

Table 1: Ten definitions of loneliness

Sullivan 1953	<i>“Loneliness is the exceedingly unpleasant and driving experience connected with the inadequate discharge of the need for human intimacy, for interpersonal relationship (p. 290)”.</i>
Weiss 1973	<i>“Loneliness is caused not by being alone but by being without definite needed relationship or set of relationships...Loneliness appears always to be a response to the absence of some particular type of relationship or, more accurately, a response to the absence of some particular relational provision (p.17)”.</i>
Leiderman 1980	<i>“Loneliness refers to an affective state in which the individual is aware of the feeling of being apart from others. Along with the experience of a vague need for other individuals (p.380)”.</i>
Peplau & Perlman 1982	<i>“Loneliness is the unpleasant experience that occurs when a person’s network of social relationships is deficient in some important way, either quantitatively or qualitatively (p.31)”.</i>
Rook 1984	<i>“Loneliness is an enduring condition of emotional distress that arises when a person feels estranged from, misunderstood, or rejected by others and/or lacks appropriate social partners for desired activities, particularly activities that provide a sense of social integration and opportunities for emotional intimacy (p. 1391)”.</i>
Rokach 1990	<i>“Loneliness is as natural and integral a part being human as are happiness, hunger and self-actualisation. Humans are born alone, they experience the terror of loneliness in death, and often much loneliness in-between (p.41)”.</i>

Younger 1995	<i>“Loneliness is the feeling of being alone in spite for longing for others. The lonely experience a sense of utter aloneness as well as aimlessness and boredom (p. 59)”.</i>
de Jong Gierveld 1998	<i>“Loneliness is a situation experienced by the individual as one where there is an unpleasant or inadmissible lack of (quality of) certain relationships. This includes situations in which the number of existing relationships is smaller than is considered desirable or admissible, as well as situations where the intimacy one wishes for has not been realised. Thus loneliness is seen to involve the manner in which the person perceives, experiences, and evaluates his or her isolation and lack of communication with other people (p. 120)”.</i>
Killeen 1998	<i>“Loneliness is a condition that describes the distressing, depressing, dehumanising, detached feelings that a person endures when there is a gaping emptiness in their life due to an unfulfilled social and/or emotional life (p. 764)”.</i>
Anderson 1998	<i>“Loneliness is the generalised lack of satisfying personal, social, or community relationships (p.282)”.</i>

Sullivan (1953) describes loneliness as the need for interpersonal relationships with others. When such needs are not fulfilled, loneliness is experienced. Needs for attachment and intimacy are the key aspects of this definition. People who fail to discharge their needs of love and ‘closeness’, thus attachment, with others are vulnerable to loneliness. Therefore, according to Sullivan, the unfulfilled needs of attachment and intimacy are the main cause of loneliness. The definition highlights how important is the way people experience and perceive their interpersonal and intimacy relationships with others. One key limitation of the former definition is that disregards the importance of one’s social needs. Both social and intimacy relationships determine loneliness since the two, in our understanding, relate to each other. Social relationships are equally important to intimacy relationships in order a person to feel complete and thus not lonely. That is, both unfulfilled intimacy and social needs may cause loneliness. The latter aspect of loneliness is lacking the attachment definition proposed by Sullivan.

Weiss’ (1973) interactionist approach views loneliness to occur when there are unfulfilled social needs for relationships or set of relationships, and not simply because someone is being alone. He defines loneliness as the absence of particular type of relationships or the absence

of particular relational provision. Similar to Sullivan's definition of loneliness, he gives weight to the deficiencies of one's relationships in causing loneliness. However Weiss, as opposed to Sullivan believes that deficits both on one's social and intimacy needs cause loneliness. When the social needs of relationships cannot be met then loneliness occurs. People are prone to experience loneliness not because they are alone, but because they are unable to fulfil their social needs for relationships. In his definition the significant aspect of loneliness, intimacy relationships, is not apparent. The latter could be thought of as a shortcoming; however in his theoretical approach to loneliness Weiss gives equal weight and thoroughly explains the role of both the social and intimacy (emotional) relationships in the occurrence of loneliness (Victor *et al.*, 2005). Many years later, Killeen (1998), directly influenced by Weiss definition of loneliness, described loneliness as a dehumanising condition resulting from the emptiness that people feel because of their unfulfilled social and emotional life. Two main points need to be noticed in Killeen's definition of loneliness. Firstly the pervasive, hurtful and depressing feelings that one endures when experiencing loneliness. Secondly the influential emotional and social distinction of loneliness by Weiss. Killeen's definition takes into consideration both the social and intimacy needs. People endure loneliness because they cannot fulfil their needs through intimate social relationships. According to Killeen, therefore, deficits to social and emotional relationships are vital in causing loneliness. This definition is one of the most complete definitions of loneliness for three main reasons: a) describes the unbearable aspect of the condition, b) gives equal weight to the deficits of social and emotional relationships, c) does not view loneliness as a pathological condition, but as a situation that anyone could endure.

Loneliness for Leiderman (1980) is the state where one is aware of being apart from others and experiences a continuous need for them. Leiderman's definition, it could be argued, highlights both one's cognitive process and one's need to relate with others. Leiderman argues that the awareness of the lack of relationships with others causes loneliness. That is, people are aware of the state of being alone, and thus experience loneliness. According to this definition cognition is one key aspect of loneliness. People with deficits in cognitive abilities (minimally or modified independence), however, seem to be neglected from the former definition. Low cognitive abilities do not necessarily mean non-comprehension of loneliness. The definition ignores a large proportion of the population which is older adults, and thus fails to depict an integrated picture of the concept. It is also not clear whether lack of certain types of relationships or all types of relationships determine one's feeling of loneliness. The

definition, however, acknowledges the significant role of one's needs and their fulfilment in the understanding of loneliness.

Peplau and Perlman (1982) define loneliness as an unpleasant experience. According to them loneliness occurs when there are deficiencies to one's social relationships, both qualitatively and quantitatively. Three main points are derived from the above definition. Firstly loneliness is an unpleasant condition which may have adverse effects on peoples' lives. Second social deficiencies are one key element in causing loneliness. Thirdly not only is the quantity of the social relationships significant but also the quality of them. That is, people may endure loneliness both because of the lack of an 'enough' number, according to one's desires, of social contacts and lack of a 'good quality', according to one's wishes, of social contacts. This applies to what was stated earlier that someone might feel lonely even when they are surrounded by a crowd, and highlights the subjective nature of loneliness.

According to Rook (1984) loneliness is an unpleasant condition which causes emotional distress, and occurs when a person feels rejected by others or lacks opportunities both for social integration and emotional intimacy. According to Rook loneliness should be viewed as the lack of social opportunities for a person to get close to others. In this definition the objective features of loneliness are described. That is, lack of opportunities for social integration and emotional intimacy through estrangement, marginalisation and rejection result to experiences of loneliness. The role of society on the way people experience and perceive loneliness is apparent in Rook's definition of loneliness.

Rokach (1990) defines loneliness as a natural inner component of human being similar to feelings of joy, hunger and self-realisation. Rokach views loneliness as being present during both birth and death, and that we are vulnerable to it experiencing throughout our lives. In this definition Rokach attributed two elements of loneliness: pervasiveness and 'esotericism'. The pervasiveness nature of loneliness is present since we endure loneliness during all stages in our lives with our first contact with loneliness to be generated during our birth and the last during our death. On the other hand by attributing loneliness a 'natural inner component nature' we accept the esotericism element of loneliness which is nothing more but our perceptions, opinions and understandings about us and things around us. It could be said that Rokack attributed a very dark and grim aspect of loneliness, yet his definition provides a

clear understanding of how loneliness consists of an integral part of our identity, of our nature, of being human.

According to Younger (1995) loneliness is the state of being alone during one's need for closeness to and connectedness with others. It is the experience of boredom, aloneness and aimlessness. The pervasiveness nature of the condition and its debilitating effects are key components in Younger's definition. However Younger describes loneliness as an experience similar to aloneness. Aloneness is a concept similar to loneliness but inherently different, and thus should not be used interchangeably (section 3.2.2). When someone is alone does not mean that he/she feels lonely. The interchangeably use of the two concepts (aloneness/loneliness) which are different in nature and context is the main shortcoming of Younger's definition of loneliness.

De Jong Glerveld (1998) describes loneliness as a situation that results from the discrepancies between an individual's wished and real social relationships. People who wish to have more social and intimacy relationships than the ones they already have might be vulnerable to loneliness. In this definition of loneliness de Jong Glerveld seems to give weight to cognitive processes. That is, the way people think, experience, and evaluate their social interaction with others associates with loneliness. When people do not have great expectations or desires from their social relationships, or when people are pleased with the amount of their social relationships, they are less likely to endure loneliness. The de Jong Glerveld's definition seems to be influenced by the Peplau and Perlman's discrepancy definition of loneliness. In both definitions three key elements appear: subjectiveness, discrepancies of social relationships and cognitive processes. Both definitions, however, do not take into consideration the socio-cultural norms and values that an individual subscribes to.

Loneliness has been defined by Anderson (1998) as the deficiencies of a satisfied number of interpersonal, social, or community relationships. Anderson's definition of loneliness gives weight to one's quantity of intimacy and social relationships. This definition fails to involve the key role of the quality of one's relationships upon loneliness. People who have a big social network might feel lonelier from people with a small social network. This is because the quality of the relationships, and not only the quantity of them, play a vital role in peoples' experiences of loneliness.

There are several definitions of the concept of loneliness. The definitions of loneliness present similarities and differences. One of the similarities lies in the description of loneliness as a debilitating condition. Deficiencies in one's relationships and unfulfilled needs are also two aspects of loneliness highlighted across almost all the aforementioned definitions. However some definitions stress out the important role of social needs, others the role of emotional needs, where a few underline the role of both social and emotional needs. In some definitions cognitive process have a key role in the understanding and occurrence of loneliness, while in some others loneliness is interchangeably used to other similar concepts. Despite the differences and similarities on the definitions of loneliness, three aspects of the concept is universally agreed upon, that is the pervasive and subjective nature of loneliness which occurs due to deficiencies in our lives.

3.2.1 Theoretical approaches on the conceptualisation of loneliness

Perlman and Peplau (1982) have suggested that eight theoretical approaches to loneliness exist, yet four theories are considered to be significant and elaborative on the concept of loneliness (Donaldson & Watson, 1996, Victor *et al.*, 2002). These predominant theories are the interactionist, psychodynamic, existential and cognitive (table 2) which are discussed below.

Table 2: Theoretical approaches that describe the concept of loneliness

Spokespersons	Theoretical approach	Propositions
Weiss (1973)	Interactionist approach	Emotional and Social Loneliness. Humans deficits of their social needs cause loneliness
Sullivan (1953) and Fromm-Reichmann (1959)	Psychodynamic approach	Human deficits of their attachment relationships cause loneliness

Tillich (1952) and Moustakas (1972)	Existential approach	Anxiety and True Loneliness. Separateness is the main cause of loneliness
Peplau & Perlman (1982)	Cognitive approach	Evaluation of humans relationships against standards of social relations cause loneliness

Robert Weiss is considered a leading representative of the interactionist approach. The interactionist approach is an attachment theory which proposes that loneliness results by the combination of the absence of an adequate social network and the lack of an intimate figure (Singh & Kiran, 2013). In 1973, his book titled, *Loneliness: the Experience of Emotional and Social Isolation* paved a new path on the way that loneliness is examined, perceived and conceptualised. He proposed that loneliness is the deficiency of one's basic need for intimate relationships which occur when one's social needs are inadequately met. According to Weiss, the basic social needs of an individual are: a) *attachment*: the social need that stems from one's intimate relationships such as friendship, marriage and family which provide safety and emotional stability; b) *social integration*: which refers to the need for belonging to social networks in order to share experiences, common interests and to communicate information and knowledge; c) *opportunity for nurturance*: one's need to be responsible and care for another person; d) *reassurance of worth*: the person's perception of him/herself as capable of maintaining a significant social pattern; e) *sense of reliable alliance*: this need stems from the person's anticipation to perceive reliable love, care and help from other people (relatives or non-relatives) even if there is no such mutual relationship between the two parties; f) *obtaining of guidance*: the need for guidance and help from a person who is more experienced, an idea that is linked with people's feelings of connectedness (Vogiatzoglou, 2008). Deficiencies in the experience of such needs results in lost opportunities for social interactions and ultimately an increased risk of loneliness.

Weiss (1973) also argues that there are two distinct types of loneliness: emotional loneliness and social loneliness. Weiss's distinction of loneliness into two different components

emerged from his evaluation about what social or intimate relationships can offer to individuals (Donaldson & Watson, 1996). Therefore emotional loneliness is resulting from the lack of emotional connections that are caused by deficiencies of intimate relationships. Loss of a loved one, divorce, and absence of friends are only some of a number of facets which form this type of condition. On the other hand social loneliness is resulting from the lack of social relations. Relocating, unemployment, being excluded from community organisations, and not belonging to groups are some examples of this type of loneliness. Both forms of loneliness involve its own symptoms. The emotional loneliness may cause anxiety, and hostility and the social loneliness may cause boredom, marginality and restlessness (Vogiatzoglou, 2008). Weiss theoretical approach has been criticised as it attributes the causes of loneliness solely on negative factors. Studies examining loneliness, however, reveal that other factors, not necessarily negative, such as age (Holmén *et al.*, 1992; Drageset *et al.*, 2011) culture (Chalise *et al.*, 2010; Lou & Ng 2012; Fokkema *et al.*, 2012), gender (Thomopoulou *et al.*, 2010; Wang *et al.*, 2011; Maes *et al.*, 2015) are often involved in causing loneliness. Researchers are benefited from Weiss's distinction of loneliness and particular researchers who aim to examine loneliness in later life, despite the critics. Victor *et al.*'s, (2005) argument adds weight to the later. They state that the theoretical and conceptual frameworks of studies which are aiming to measure loneliness across the life span are linked with the Weiss's distinction of loneliness. This explain why the interactionist theory and Weiss's dichotomisation of loneliness has been influential to this study's second phase (qualitative approach).

A second theoretical approach for the conceptualisation of loneliness comes from the psychodynamic theorists. Sullivan (1953) and Fromm-Reichmann (1959) are two of the main spokespersons of the psychodynamic approach (Perlman & Peplau, 1982). According to this approach deficits in people's attachments that stem from infant and childhood periods are considered to cause loneliness in later life. People have a need for intimate relationships since infancy which are depicted as a need for contact with their parents. People who lack the social skills to develop intimate relationships in childhood are more likely to experience loneliness in later life. Proponents of this theory view loneliness as a pathological phenomenon which occurs when difficulties to form social relationships exist because of the absence of social skills (Donaldson & Watson, 1996). The psychodynamic approach provides useful information for the concept of loneliness from a clinical perspective. That is, the psychodynamic conceptualisation of loneliness is based solely on clinical observations of

people with mental illness (Perlman & Peplau, 1982). Therefore, from a psychodynamic perspective loneliness is a state of mind which is symptomatic of neurosis (Singh & Kiran, 2013). The conceptualisation of loneliness based solely on clinical observations is one of the main shortcomings of this theoretical approach (Perlman & Peplau, 1982). The approach does not take into account the social world of the person (Donaldson & Watson, 1996) which potentially could have a key role in the experience of loneliness. Notions such as culture, age and bereavement that have been found to affect loneliness, particularly among older adults, are ignored by the traditional psychodynamic theorists.

Another theoretical approach which attempts to describe the concept of loneliness is the existential theory. Two leading advocates of this approach are Tillich (1952) and Moustakas (1972). According to them all people are “ultimately alone” and loneliness stems from separateness which is “an existential condition of people’s existence” (Perlman & Peplau, 1982, p. 126). They also dichotomise loneliness into anxiety and true loneliness. True loneliness stems from the actual deficits on one’s social relationships. These deficits cause feelings of being alone to occur, and highlight the lonely process of one’s experiences in life such as death, and birth. Anxiety loneliness refers to the response mechanisms that people develop in order to avoid facing crucial life situations. The latter underlines one’s constantly need to search out for social contacts (Perlman & Peplau, 1982). The approach has also been criticised that perceives loneliness from a clinical perspective and it presents the concept as more mysterious and complex than it is necessary (Singh & Kiran, 2013). The existential theory makes no distinctions between the subjective notion of feeling alone and the objective notion of feeling alone (Donaldson & Watson, 1996) which is one of its key limitations. Therefore people who prefer to be alone are perceived by the existential theorists as lonely, yet this may not be entirely true.

The cognitive approach attempts to conceptualise loneliness by identifying the important role of the social factors on the notion of loneliness. Moreover this approach underlines the influential role of the personality of an individual on the way that the person perceives and experiences his/her loneliness. Two of the main adherents of the cognitive theory Peplau and Perlman (1982), suggest that loneliness is a situation that people can manipulate and cope with. Cognitive theorists propose that the evaluation of one’s social relationships against some stereotypical ideal standards of social relations is the main component that leads to experiences of loneliness. People who think that deficits to their social relationships exist are more likely to experience loneliness (Booth, 1983; Donaldson & Watson, 1996). This

approach therefore emphasizes as a key factor in determining the way people feel about their condition (Singh & Kiran, 2013). Cognitive theorists give much weight to one's social skills and self-esteem in alleviating loneliness. One key limitation of this approach is that ignores people with cognitive impairment and fails to acknowledge the importance of one's social networks.

Heinrick and Gullone (2006) stated that loneliness is a fundamental fact in humans lives and that every human may experience loneliness at some point of his/her existence. Wood (1986) goes so far as to suggest that "failure to experience loneliness appropriately calls into question one's very nature as a social being" (cited in Wright, 2007, p. 26). Loneliness is a phenomenon which affects every person at some point of his/her life. However, there is no consensus among scholars on the definition and conceptualisation of loneliness because of its universal and subjective nature. The different types of theoretical approaches of loneliness underline the complexity of the phenomenon. Nevertheless scholars seem to agree that loneliness is a pervasive feeling. The multi-dimensional and subjective nature of the concept explains why none of the theoretical foundations of loneliness has been entirely adopted, in this study. However Weiss's distinction of loneliness has been influential to this study's qualitative phase (chapter 9, section 9.2.2).

3.2.2 Other related concepts to loneliness

Loneliness is comprehended, perceived and experienced differently by each individual, and thus it is important to distinguish loneliness from other related concepts. Loneliness should not be confused with other related concepts which are often used interchangeably.

One concept that is often confused with the concept of loneliness is that of aloneness or being alone. However, a subtle line separates the two. Loneliness is the condition in which the person feels lonely and has no choice on the situation (Killeen, 1998). That is, loneliness conveys a negative meaning and does not allow the person to avoid its pervasive and deliberating outcomes. Aloneness on the other hand is the situation in which the person might be alone, yet does not feel lonely. Aloneness indicates a more 'conscious condition' in which the person may prefer or may have the choice to be alone. Jacobs (1978) argues about the two concepts that "there is no direct link between the two concepts (aloneness and loneliness): you can be lonely in a crowd, and you can be happy alone, but as a rule, it would be expected that people are more likely to feel lonely when they are by themselves (p. 25)".

Social isolation is another concept which is often misinterpreted with the concept of loneliness. Social isolation can be considered as the ‘intermediate concept’ between the concept of loneliness and aloneness, while it can also be thought of as the objective aspect of loneliness. Therefore, it is a quantifiable, objective reflection of lack of social or intimacy relationships. According to Killeen (1998) social isolation with a choice on the matter is aloneness whether social isolation without choice on the matter is loneliness. The distinct line between the concept of loneliness and the concept of social isolation is considered to be the choice that people indicate on the situation. However whether the person will reach to the objective continuum of the condition (social isolation) or not depends on his/her subjective notions of his/her social relationship patterns (de Jong Gierveld *et al.*, 2006). Therefore people who choose to be socially isolated might not feel lonely and people who feel lonely might not be socially isolated.

Solitude is another interchangeably linked concept to loneliness. The concept conveys a more positive sense in comparison to loneliness (Bekhet *et al.*, 2008). According to Ishmuhametov (2006) “the main difference between the notion of “loneliness” and “solitude” lies in the fact that the latter is not connected with the negative emotional evaluation of a state (p. 83)”. For some people therefore solitude might indicate the voluntary way to spirituality and self-fulfilment. Other scholars such as Killeen (1998) and Bekhet *et al.*, (2008) suggest that the concept of solitude provides total freedom and can be a very calming and refreshing experience. Solitude therefore carries an optimism connotation which may affect positively the personality of an individual.

Loneliness is a complex phenomenon and its close relation to other multidimensional concepts creates more confusion on the comprehension of its nature. Loneliness, aloneness, social isolation and solitude are related concepts which often used interchangeably. Each of the above discussed concepts indicates different connotations and conveys different experiences. In a theoretical continuum therefore the concept of loneliness is on the negative side while the concept of solitude is on the positive side, where aloneness and social isolation stand in between.

3.3 Prevalence and experiences of loneliness among older adults

Holmén *et al.*'s (1992) cross-sectional study examined experience of loneliness and its association with social contacts and health among the elderly living in Stockholm. The study

made use of a self-reporting question to assess loneliness among 1725 older adults (aged 75+ years). The findings revealed that 35% of the sample experienced loneliness. Constanca *et al.*, (2006) measured prevalence of psychological distress and loneliness (using a structured questionnaire that included one single loneliness-question) among 999 UK community dwelling older adults (65+). The findings revealed that 7% of the participants between the ages of 70-79 years were often or always lonely, with the percentage increasing to 13% among those aged 80 years old and older.

Victor *et al.*, (2002) investigated the extent to which loneliness among UK-based older adults changes over time. The researchers compared historical with contemporary cross-sectional studies that utilised the same definitions of loneliness, and implemented similar methodological approaches. Comparisons were made between the Sheldon (1948), Townsend (1957) and Tunstall (1963) studies and the South London Health Survey (Shah, *et al.*, 2001). Their findings revealed that the prevalence of loneliness was reported to be between 6% and 9% with no significant increases between 1948 and 2001. Victor and Bowling (2012), in a longitudinal study, assessed prevalence of loneliness and how this has changed over time among UK-based community dwelling older adults (aged 65+ years). Among the 287 respondents who participated in the follow-up study, 9% of them were severely lonely, while 30% of them sometimes lonely. Prevalence of loneliness comparisons revealed that 60% of the participants indicate a stable rate of loneliness

Beaumont's (2013) secondary analysis of the English Longitudinal Study of Ageing (ELSA) found that 17% of participants aged 80+ are often lonely compared to an average of 9% across all participants (50 years +). Also the study reveals that 59% of adults aged over 52 years who suffer from poor health feel lonely some of the time or often, compared to 21% who say they are in excellent health. These findings suggest that the oldest age groups with poor health endure comparatively higher levels of loneliness.

Pikhartova *et al.*, (2014) investigated the relationships between pet ownership and loneliness among 5210 older adults (aged=50+) in the UK. The authors used data from Wave 2 (2004) and 5 (2015) from the ELSA longitudinal study. Their findings revealed that prevalence of loneliness was 18.1% in Wave 2, and 20.6% in Wave 5 across all groups. Both Waves, however, revealed higher levels of loneliness across female participants (Wave 2=21.3%, Wave 5=23.9%). They also found that there is a strong relationship between pet ownership

and loneliness among women. The relationship was strong in both directions (loneliness predicts pet ownership, and pet ownership predicts loneliness). The authors argued that “pet ownership can be a response to loneliness for the always lonely and a protection for those who recovered from loneliness (p. 9)”, and concluded that loneliness is a culturally constructed phenomena. In another study Pikhartova *et al.* (2015) examined the relationships between stereotypes of loneliness in old age and ‘actual’ loneliness. They also used data from the ELSA which had collected loneliness data through the 3-item ‘UCLA loneliness scale’. The sample was older adults (50+) participated in Waves 2, and responded to loneliness questions at least once between Waves 3 and 6 (n= 4465). The findings indicate that across Waves 3 and 6, 11.5% of older adults feel lonely, while 24% of them considered loneliness part of the ageing process. Their findings also revealed that 33% of the sample believed that would experience loneliness in old age. The authors argued that participants who agreed with the two statements (‘be lonely in old age’ and ‘loneliness is part of the ageing process’) were 2.32 and 2.83 times more likely to report loneliness in Waves 3 and 6 respectively, compared with those who did not agree with such statements.

Drageset *et al.*, (2011), in a cross-sectional survey, investigated the relationships between loneliness and social support among 227 older adults (aged= 65+) residing in 30 nursing homes in Norway. One self-reported loneliness question was used. They found that 35% of the respondents were sometimes lonely, while 22% of them feel often lonely; that is, more than half of older adults who are residing in nursing homes report loneliness. They also found that lower social support correlated with higher loneliness, while higher attachment correlated with lower loneliness. However the cross-sectional design of this study does not allow cause and effect relationships to be established.

Slettebø (2008), in a qualitative hermeneutical study, examined the experiences of loneliness among 14 older adults residing in Norwegian nursing home. Their qualitative content analysis indicated that interviewees may feel safe in the nursing home, yet lonely, bored and sad. The latter is reflected by an informant who stated “*I think it’s very boring and sad to live here in the nursing home. I have no one to talk to.... Sometimes the nurses go outside and smoke..... When the nurses smoke, I drive my wheelchair out to them and smoke because I want someone to talk to. Here there is nobody to talk to – it makes my day long and boring. I really wish the nurses would take some time to talk to us*”. The words of the participant reveal the unpleasant feeling of having no one to talk to which triggers loneliness to arise.

The authors concluded that loneliness is present and a serious problem among older adults in nursing homes.

Similar findings have been documented by Heravi-Karimooi *et al.*, (2010) who explored experiences of loneliness under the context of a qualitative hermeneutical phenomenological approach among 13 older adults (65+ years old) living in the community (Iran). The findings revealed four major themes: a) ‘an aversive emotional state’ (“negative, tormentor, terrible and very painful feeling” p. 276), b) ‘isolated from intimate relationships’, c) ‘being deprived from social and external support systems’, and d) ‘being abused and neglected’. Feelings of sadness, feelings of abandonment, lack of intimate relationships and lack of companionship were some among other facets that contributed to loneliness among the respondents.

Evangelista *et al.*’s (2014) recent study reports similar findings. They interviewed 14 Brazilian older adults in nursing homes (age range: 60-92 years). Their thematic analysis revealed feelings of abandonment and loneliness because of limited contacts with children; anger and ingratitude because they felt unhappy with the final stages of their lives; living with chronic pain; satisfaction of property in the nursing home refers to feelings of being satisfied with the nursing home context; productivity which refers to participation of activities and accomplishment of goals; social relationship among respondents which refers to residents opportunities to form and interact with people experiencing similar life changes, and find support between them.

Iden *et al.* (2015) explore perceptions of sadness among 12 Norwegian residents in nursing homes (aged 80+) using a semi-structured qualitative approach. Their primary aim did not involve the exploration of experiences of loneliness among this population. However loneliness was one of their key findings. Lack of communication with family members, staff members and fellow residents, and the death of family and spouses caused experiences of loneliness. Also residents experience sad mood because of their physical health problems and the poor care provided by nursing home staff. Accepting the changes of old age, feeling grateful for retaining functional abilities, retaining connection with own and family’s life history, and religious activity were key coping mechanisms of loneliness among residents.

For more than 50 years loneliness has been reported in the health and social care research literature as a dominant problem with pervasive outcomes for older adults (Theeke, 2009).

This is succinctly reflected in Sheldon's (1948) words that "loneliness is a well-known calamity of old age (p. 127)". However as Valtorta and Hanratty (2012) poignantly state "the absence of universally accepted definitions and the difference in the phenomena observed, as well as the range of indicators and measurement tools (p. 519)" result in variations on loneliness estimates and make loneliness-related studies challenging for researchers. This literature gives weight to these propositions. Prevalence of loneliness seems to vary based on methodological approaches, loneliness tools, settings and cultural contexts, and makes comparisons problematic. However loneliness is present and a significant challenge for this population, and particularly, among older adults in nursing homes (22% Dragaset *et al.*, 2011). The studies, however, exploring and/or examining loneliness among UK-based older adults in nursing homes are limited.

3.4 Factors associated with loneliness among older adults

Literature on loneliness among older adults reveals that several factors associate with loneliness among this age group. Socio-demographic factors, social contacts and relationships, and psychological well-being (figure 6) are only some of the many factors have been examined over the years in relation to loneliness. The discussion of relevant literature is key for this study, and particularly the relationships between loneliness and socio-demographic factors since one of its objectives examines how socio-demographic variables explain prevalence of loneliness among mentally ill older adults nursing homes.

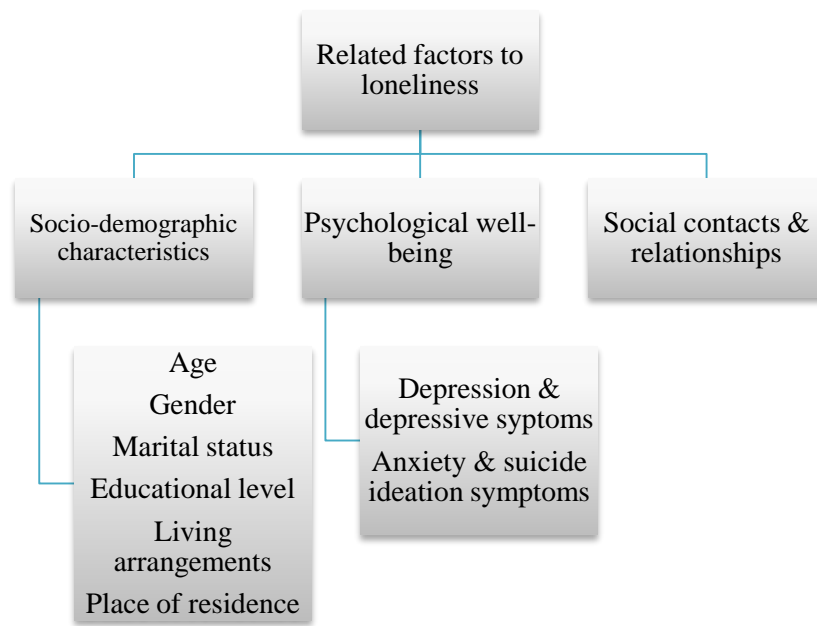


Figure 6: Factors related to loneliness among older adults

3.4.1 Loneliness and socio-demographic factors

Loneliness seems to be associated with ageing however studies report variations. For example, Holmén *et al.*, (1992) in a sample of 1725 Swedish older adults (age range 75-101 years), revealed that levels of loneliness increase until the age of 90, with highest levels to be in those aged 83. However levels of loneliness decreased after the age of 90+ years. The authors argue that loneliness decreases because of the familiarity of this age group with loneliness. Victor *et al.*, (2005) argues that advanced age is a protective factor against loneliness.

Findings from other studies however suggest that loneliness is higher among the oldest older adults compared to their younger counterparts (Hazer & Boyle, 2010; Shankar *et al.*, 2011; Dong *et al.*, 2012). For example Constanca *et al.*'s (2006) study of 999 community dwelling older adults found that loneliness was higher among participants aged 80 years or more compared to younger counterparts. This is further supported by longitudinal studies. Tijhuis *et al.*'s (1999) longitudinal study examined the relationships between loneliness, age, cohort and time trends. Cohorts were followed up every five years until 1995. The findings revealed that experiences of loneliness were higher for the oldest participants.

However in several other studies a meaningful relationship between loneliness and age has not been identified (Theeke, 2009; Prieto-Flores *et al.*, 2011). There is an inconsistency in the literature whether age directly associates with loneliness or not. The methods, settings, cultural contexts and the aging process itself could partially explain this inconsistency. That is, getting older signifies many life changes. Therefore, loneliness associates with ageing because of the life changes older adults' might face (poor physical and mental health, losses, dependency) during the final stages in life, and not because of the ageing process itself.

Loneliness also associates with gender. Studies suggested that women report higher levels of loneliness compared to men (Thomopoulou *et al.*, 2010; Nicolaisen & Thorsen 2014; Simon *et al.*, 2014). Life expectancy between genders may partially explain these findings. That is, women tend to live longer compared to men. This may constitute women being more vulnerable to situations of widowhood and/or bereavement; conditions that trigger loneliness to occur. Tijhuis *et al.*, (1999) argued that social and emotional relationships are valued greater by women than men. Women are considered as more sensitive and emotional insecure beings, which results in higher levels of loneliness among them. It is worth mentioning however, that there are studies that report no gender differences on levels of loneliness (Wang *et al.*, 2011).

Many studies demonstrate the relationship between loneliness and widowhood (Hazer and Boyle, 2010; Aartsen & Jylha, 2011, Bennett & Victor, 2012) divorce (Constanca *et al.*, 2006; Yang & Victor, 2008; Hazer & Boyle, 2010), and being single (Yang & Victor, 2008; Theeke, 2009; Thomopoulou *et al.*, 2010). Zettel and Rook (2004), in a longitudinal study, aimed to examine social network substitution and compensation among 322 older women (60-80 years old) who had lost their spouses. Participants were interviewed seven times in one year period time and represented three cohorts: widowhood between 3-6 months, 15-18 months, and 27-30 months. Widows in all cohorts scored higher on the loneliness scale, and particularly widows who had a significant number of new social relationships. The findings indicate no decrease in loneliness because of new social networks (Beal *et al.*, 2006). Dahlberg *et al.*, (2015) used data from the SWEOLD longitudinal national survey (n = 587) to examine the extent of loneliness among Swedish older adults (aged 70+ years). The authors found that loneliness significantly correlates with recent widowhood. Widowed older adults feel the loss of their intimate and confident relationships which causes loneliness.

Living arrangements also associate with loneliness. For example, older adults who are living alone are more likely to experience loneliness (Lim & Kua, 2011; Koc, 2012). In addition, older adults in nursing homes and residential home cares report high loneliness (Slettebø, 2008; Drageset *et al.*, 2011; Iden *et al.*, 2015). A study by de Jong-Gierveld and Kamphuis (1986) examined loneliness among older adults in two times (previous and after older adults' admission in the residential care home). They revealed that loneliness is higher among those who state 'loneliness' as reason for admission. Nevertheless after admission both groups (independently of reason of admission) report no variations in loneliness levels (cited in Savikko, 2008). However, it is still unclear about the breadth and depth of loneliness among older adults in nursing homes.

Educational achievement also correlates with loneliness among this population. Koc (2012) in a cross-sectional study among 330 Turkish older adults demonstrated this by reporting that low educational level is associated with higher levels of loneliness. In a UK-based survey, Victor *et al.*, (2005) in a sample of 999 older adults revealed that higher educational levels act as protective factors against loneliness in later life. Similar findings were reported by a more recent study. Teh *et al.*, (2014) examined factors associated with loneliness among older adults aged 60+ years living in Malaysia with children. Data from the 2004 Malaysian Population and Family representative survey were used (n=1791). The sample involved Malaysians, Chinese, Indians and other Indigenous groups. Their findings indicated that those with higher education were less likely to report loneliness across the Malaysian and Indigenous participants. No correlation was reported between educational level and loneliness in the Chinese group. One explanation for this could be that highly educated older adults would fare better compared to their low educated counterparts. This gives them the opportunity to participate in more social activities, have more hobbies (Koc 2012), and therefore maintain their social relationships intact.

Place of residence may also increase or decrease the risk of experiencing loneliness. For example, a study in Wales by Drennan *et al.*, (2008) indicated that older adults who were residents of rural areas reported higher levels of loneliness compared to their counterparts living in urban areas. The authors argued that urbanisation results in fewer opportunities of social relationships and social integration for older adults in rural areas, which causes loneliness to increase.

To summarise, age, gender, marital status, living arrangements (living alone/residing in residential care homes or nursing homes) educational level, and place of residence are some of a number of factors that correlate with loneliness among older adults. The literature presents variations on the relationships between loneliness and socio-demographic factors, with some of the relationships being consistent across studies (e.g. educational level), others inconsistent (e.g. age), and others needing further investigation (e.g. older adults in nursing homes). This study attempts to set light both on the prevalence of loneliness and to the extent that particular socio-demographic factors correlate with loneliness among older adults in nursing homes. Culture is also a significant factor in explaining loneliness, and key to this study; therefore it is discussed separately in chapter 5, section 5.2.

3.4.2 Loneliness, social contacts and social relationships

The evidence across the loneliness literature indicates that both a limited social network which is characterised by a low frequency of contact with family members (Eshbaugh, 2009; Losada *et al.*, 2012; Medvene *et al.*, 2015), friends (Eshbaugh 2009; Losada *et al.*, 2012), neighbours (Drageset, 2004), or significant others (Wilson & Moulton, 2010; Victor & Bowling, 2012; Roos & Malan, 2012) is associated with loneliness.

Demakos *et al.*'s (2006) cross-sectional study, among UK-based older adults, revealed that older adults who retain contact with their children are less likely to feel lonely, with the quality and frequency of the contact also making a key difference. That is, older adults who had no close relationship with their children reported consistently higher levels of loneliness compared to their childless counterparts. In addition older adults who had less frequent and/or no contact at all with their children (either by phone or face-to-face) reported higher levels of loneliness compared to those who had frequent contact with their children (at least once or twice a week). The authors concluded that both the quality (close relationships), and the quantitative of the relationships are key detractors of levels of loneliness among older adults.

In a systematic review and meta-analysis of the loneliness literature, Pinquart and Si Sörensen (2001) found that, across the majority of the studies identified, the quality of older adults' social relationships was more important than the size of their networks. However, Hawkey *et al.*, (2008) revealed that the networks size is also one key protective factor against loneliness among older adults. Data were used from a population-based sample of 225

White, Black, and Hispanic aged 50-68 participated in the Chicago Health, Aging, and Social Relations Study. The authors found that large social networks associated with lower levels of loneliness. The results remained the same independent of the quality of the relationships between the members. The authors argued that large social networks provide a safe environment to establish good quality relationships which explains why social networks size associates with lower loneliness. They also argued that the ability to create and form social networks, and therefore social connections, is a protective factor against loneliness among this population.

Feraira-Alves *et al.* (2014) aimed to examine the levels and relationships between loneliness and socio-demographic characteristics (other than age) among 1174 Portuguese aged 50+ years old. They found that loneliness significantly correlates with a number of socio-demographic variables such as age, gender, marital status, living arrangements, region, residential settings, type of housing, professional status, and income. They also found that satisfaction with social networks and activities correlates with loneliness among this age group. More specifically, older adults with less social satisfaction reported higher loneliness. The findings therefore support the proposition that limited and/or lack of social relationships, contacts, networks, and social participation which triggers low social satisfaction correlates with higher loneliness among this age group.

The findings indicate that loneliness among older adults depends on the quality of the relationships and not only the quantity of them. These findings provide grounds for theory building on loneliness among older adults in nursing homes. Older adults who are residing in nursing homes may often endure loneliness because of the lack of quality in their social and intimacy relationships.

3.4.3 Loneliness, psychological well-being and mental health status

Psychological well-being and absence of mental health problems are indicators of quality of life across the ageing population (Savikko, 2008). However older adults' quality of life is undermined by the emotional effects of loneliness upon their psychological well-being.

For example, depression and depressive symptoms have been widely found to be significantly associate with loneliness among older adults (e.g. Bekhet & Zauszniewski, 2012; Aylaz *et al.*, 2012). Cacioppo *et al.*, (2006) found that depressive symptoms were

significantly associated with loneliness among adults (aged 54+) even when controlling for other risk factors of depression. When depressive symptoms correlate with loneliness then problems of older adults' psychological well-being may become bigger.

Bekhet and Zauszniewski (2012) examined associations between loneliness and mental and physical health among 314 older adults residing in retirement homes in Northern Ohio. The authors used a cross-sectional study design. The findings revealed that lonely older adults had higher depressive and anxiety scores than elders who were not experiencing loneliness.

Recent studies reveal similar findings. For example, van Beljouw *et al.*, (2015) examined mental health and loneliness among older adults (aged 65+ years) with depressive symptoms. Two hundred and forty nine community-dwelling Netherlands with depression were recruited in a mixed-methods design study. The findings revealed that depressed older adults endured high levels of loneliness (87.8%). Poorer mental health outcomes were also identified among the lonely older adults compared to the older adults who were not/mildly lonely. They also found that severe depressive symptoms, higher anxiety, current serious depressive disorder, and a current or past dysthymic incidence (a type of depression) associated with severe loneliness. The qualitative findings revealed similar results. Participants' interviews showed that there is a relationship between mental ill health and loneliness. More specifically, older adults who felt severely lonely attributed their depression to their limited social contacts and/or to feelings of loneliness.

A systematic review of the literature by Mezūk *et al.*, (2014) reported strong associations between suicide rates and loneliness. They examined suicide rates among older adults in long-term care settings over the past 25 years. Thirty seven papers were identified. The findings revealed that suicidal ideation was common among residents (5-33%), while loneliness was one key risk factor of suicidal ideation among this group. A systematic review by de Minayo and Cavalcante (2015), examining the factors associated with suicide attempts among older adults, reports similar findings. The authors analysed 75 studies between 2002 and 2013. The findings revealed that suicide attempts among this age group significantly correlated with depressive symptoms combined with loss, abandonment, loneliness, family conflict and chronic physical problems. Loneliness therefore seems to play a key role in the suicidal ideation of older adults.

To summarise, the evidence reports significant correlations between loneliness and various health problems such as depression, anxiety, and suicide attempts among older adults. Older adults' psychological well-being, therefore, relates to feelings of loneliness. The former evidence is significant for this study since one of its primary aims is to examine levels and to explore experiences of loneliness among older adults with mental health problems residing in nursing homes.

3.5 Summary

The concept of loneliness has attracted much attention from the classical era until the recent years. Scholars agree that loneliness is a pervasive and debilitating condition that is interlinked with the human nature, and thus inherently linked with ones' social and cultural contexts. There are various definitions and distinct theoretical approaches to loneliness that emphasise different perspectives of individuals' experiences. In this study none of the theoretical approaches of the concept is entirely adopted. Yet the interactionist approach has been influential to the formulation of the second phase.

Loneliness is often interchangeably used to other similar concepts. Aloneness, solitude, and social isolation are some among a number of related concepts to loneliness. Their interchangeably use with loneliness add more intricacy to an already complicated concept. Therefore their distinction from the concept of loneliness is of major importance.

The literature reveals that levels and experience of loneliness is prevalent among older adults, and documents several factors that explain, contribute, and relate to loneliness. Age, educational status, living arrangements are examples of socio-demographic factors that associate with increase loneliness in later life. Social contacts and social relationships also correlate with loneliness among older adults. Deficiencies in older adults' social environment as well as lack of quality of social contacts seem to affect feelings of loneliness among them. Loneliness also significantly associates with mental health problems such as depression, anxiety and suicidal ideation.

Chapter 4: Culture: a literature review

4.1 An introduction to culture

Culture is a concept that has attracted much research attention, and has been defined and conceptualised in various ways. A study reveals more than 150 definitions of culture within the anthropological literature (Kroeber & Kluckhohn, 1952, cited in Smith, 2000), yet culture, it is argued, remains indefinable (Frischmann, 2006). This chapter discusses the definitions of culture, while reviews the theoretical approaches, and cultural models and dimensions. It also discusses the individualism/collectivism cultural paradigm (I/C), and its four dimension cultural model - the vertical/horizontal individualism collectivism model (VHIC). Finally the chapter discusses why the VHIC model is adopted in this study.

4.2 Definitions of culture

There is no a universally agreed definition of culture. The complex nature of culture partially explains this inconsistency, since there are no clear boundaries of when culture begins and ends. Therefore, it is unclear which elements of the concept should be included in its definition, and which elements should be excluded from it. This makes a universally agreed definition of culture rather problematic.

Williams Raymond (1983) argues that “culture is one of the two or three most complicated words in the English language”, yet over the years scholars attempted to unravel this complexity (Oakes & Price, 2008, p. 16). For example, Sewell (1999), in his work *The Concept(s) of Culture*, provides a comprehensive framework of culture by distinguishing two significant conceptual meanings. He argues that one meaning perceives culture as an aspect of social life that should remain detached and disconnected from the complicated realities of human entity. The second meaning perceives culture as a “concrete and bounded world of beliefs and practices (p. 39)”. Therefore culture interrelates and is connected with the shared beliefs and practices of one’s society.

Kroeber and Kluckhohn (1952) in a systematic review of the literature also revealed culture’s various definitions. The authors identified more than 150 definitions of culture and proposed that six main over-arching definitions exist within the anthropological cultural literature:

- a) *Descriptive definitions* refer to culture as a totality that involves all the aspects of human activities and social life. That is culture defines humans' activities and social life, and, in turn, humans' activities and social life defines culture.
- b) *Historical definitions* refer to culture as a heritage transmitted from one generation to the other.
- c) *Normative definitions* may take two distinct forms. One form views culture as a system of rules that influences patterns and social behaviour. The second form views culture as a system of rules, and values without referencing to humans' behaviour.
- d) *Psychological definitions* view culture as a coping mechanism that allows people to fulfill their material and emotional needs, communicate with each other, and learn.
- e) *Structural definitions* view culture as an abstraction, while differentiate it (culture) from behavioural patterns.
- f) *Genetic definitions* "these had do little with biology, but rather explained culture as arising from human interaction or continuing to exist as the product of intergenerational transmission" (Smith, 2000, p. 3).

The various meanings attributed to the term 'culture' reveal the complex and multi-dimensional nature of the concept (Spencer-Oatey, 2012). Figure 7 presents key definitions that depict the above discussed distinctions.

<i>Descriptive definitions</i>	<ul style="list-style-type: none"> • "...as that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man as a member of society" (Taylor, 1969, p. 1)
<i>Historical definitions</i>	<ul style="list-style-type: none"> • "The culture of the group is the sum total and organisation of the social heritages which have acquired a social meaning because of racial temperament and of the historical life of the group" (Park & Burgess, 1921, p. 47)
<i>Psychological definitions</i>	<ul style="list-style-type: none"> • "...as a pattern of shared attitudes, beliefs, categorizations, self-definitions, norms, role definitions, and values that is organized around a theme that can be identified among those who speak a particular language, during a specific historic period, and in a defined geographic area" (Triandis, 1996, p.1)
<i>Structural definitions</i>	<ul style="list-style-type: none"> • "Culture is to society what memory is to individuals" (Kluckhohn, 1954, p. 60)
<i>Genetic definitions</i>	<ul style="list-style-type: none"> • "...culture is arising from human interaction or continuing to exist as the product of intergenerational transmission" (Smith, 2002)
<i>Normative definitions</i>	<ul style="list-style-type: none"> • "The mode of life followed by the community or a tribe is regarded as culture...the aggregate of standardised beliefs and procedures by followed tribes" (Wissler, 1940, p. 50)

Figure 7: Key definitions of culture (partially adapted from Smith 2000)

Smith (2002) identifies four main themes when scholars refer to culture. Firstly *culture tends to be opposed to the material, technological, and social structural*: that is, although the potential empirical relationships between them, it is essential to comprehend culture as a distinctive notion, which is abstracted out of a common way of life. Secondly, *culture is seen as the ideal, the spiritual, and the non-material*: that is, the notion of culture is shaped and understood through the spectrum of ideas, beliefs, views, values, symbols and signs. Thirdly, *emphasis is placed on the "autonomy of culture"*: that means that culture is complex and affixed, and cannot be explained only under the context of social structural needs or distributions of power. Finally *efforts are made to remain value-neutral*: culture is understood to strongly affect all the aspects of social life.

There are a number of different definitions of culture. A systematic review revealed six main definitions of culture with each of them to stress out different aspects of the concept. Scholars also identified four main themes of culture which highlight culture's multi-dimensional nature.

4.3 The concept of culture: theoretical approaches

There are a number of theoretical approaches to culture. The socio-cultural conception of culture as adaptive systems, and the ideational perception of culture as cognitive, symbolic or structural systems are perhaps two of the most important conceptual differentiations of the concept (Harrison & Carroll, 2005; Aneas & Paz Sandin, 2009) (see figure 8) that have monopolized the theoretical debates among scholars.

Four distinct schools of thought have emerged within the socio-cultural conceptualisation of culture. For the *Functionalist* conception culture is a device through which people face and cope with specific deficits in relation to their needs of satisfaction. The satisfaction of basic human needs therefore results to manifestations of culture (Allaire & Firsirotu, 1984). For example, human needs such as companionship, learning, feeding and many others need to be satisfied. Culture therefore is the device that helps and allows people to fulfill these needs. Bronislaw Malinowski is one of the main supporters of the functionalist conceptualisation of culture. He defines culture as “an instrument which enables man to secure his bio-psychic survival” (seen in Sociology Guide, 2013). He emphasises and establishes cultural pluralism by arguing that cultures are grown to satisfy the bio-psychic needs of people and should be judged based on these terms. Cultures, he proposes, are different and changeable, and thus cannot be learnt through similar causes (Day, 2012).

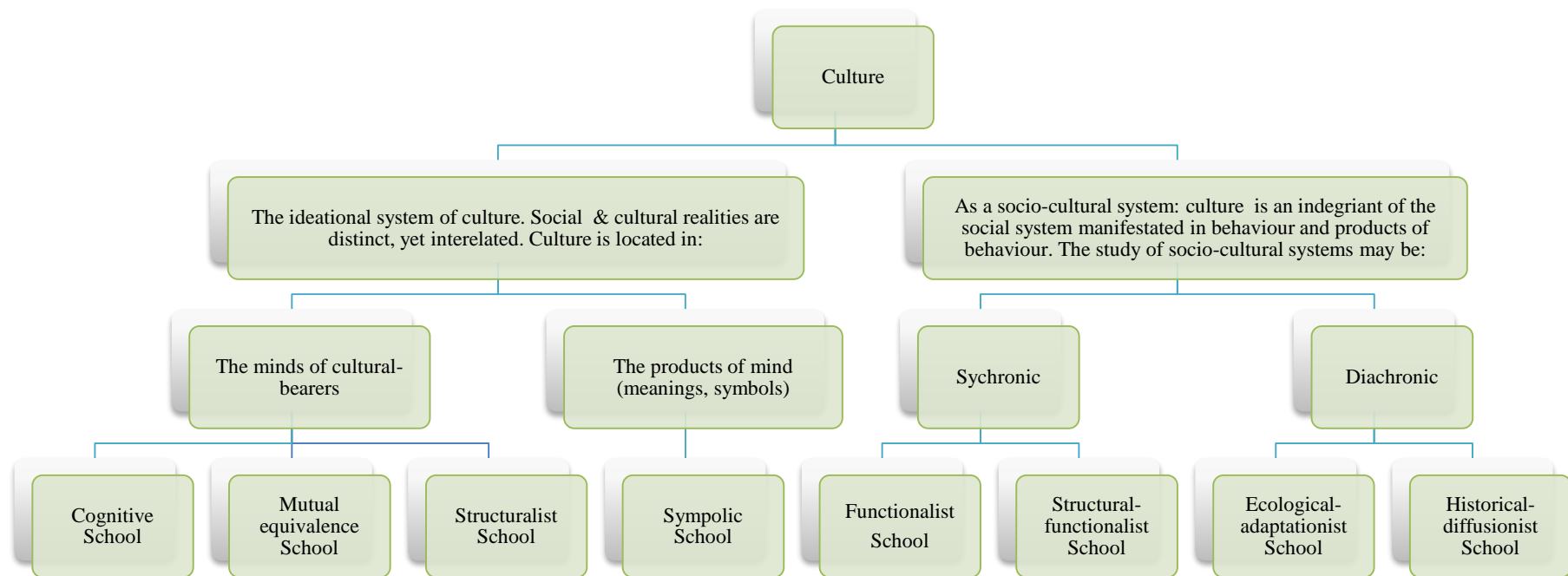


Figure 8: A typology of the concept of culture (adopted by Allaire & Firsitou, 1984)

Radcliffe-Brown was one of the proponents of the *Structural-functionalist* school. This approach views culture as an adaptive and essential mechanism that enables people to live their social lives within the context of structured and ordered communities (Allaire & Firsirotu, 1984). This school of thought gives much attention to the acculturation, learning processes and social aspect of culture that influences and forms the structures and orders of every society. It is through these structures that humans are enabled to peacefully enjoy and participate to their communities.

Another school of the socio-cultural concept of culture is the *Ecological-adaptation* view. For this school of thought culture is a system of transmitted behaviour patterns. These behavioural patterns allow humans to relate communities to environments (Allaire & Firsirotu, 1984). The relationship between communities and environments is ruled by causality and interconnectedness. None of the two constructs (environment and culture) is grounded, but they define each other. Supporters of the *Ecological-adaptation* school believe that humans' environment has a tangible involvement in the valuation of culture which on the other hand shapes the characteristics of humans' environment.

The other school of the socio-cultural conceptualisation of culture, the *Historical-diffusionist*, supports that culture is a system composed of interactive and autonomous formations (Allaire & Firsirotu, 1984; Keesing, 1974). Here autonomy is one key element. However we cannot view culture as an absolute autonomous total of formations, since culture is a complicated concept. Culture involves many different meanings and can be conceptualised within different theoretical frameworks. It is the nature of culture itself that does not allow an absolute and integrated concept to emerge. As Kluckhohn (1954), one of the main supporters of the *Historical-diffusionist* conceptualisation of culture, states, "culture is to society what memory is to individuals" (cited in Triandis, 2002, p. 135) by indicating the important role of cultures to societies, and to humans social relationships.

Tylor (1969) defines culture "as that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man as a member of society", although he argues that "cultures are not material phenomena: they are cognitive organisations of material phenomena (p. 3)" (Peacock, 2001). The anthropologist Edward M. Tylor was one of the proponents of the ideational conceptualisation of culture. That is, culture is manifested in cognitive structures, processes or products. Four main schools of thought have emerged within the ideational conceptualisation of culture. The *Cognitive*

school views culture as a system of knowledge. This system allows humans to develop standards that teach them how to appraise, behave, apprehend and believe (Allaire & Firsirotu, 1984). The latter argument is succinctly reflected to Goodenough (1957) words that "...culture consists of whatever it is one has to know or believe in order to operate in a manner acceptable to its members...(p. 167)" (cited in Riley, 2007). Thus culture serves as means of humans cognitive processes that help them to define the way they comprehend the realities around them, and the way they should behave to 'fulfill' this realities.

For the *Structuralist School* of thought culture is an unconscious process of humans' brain that leads to specific cultural manifestations. Therefore culture is a product of humans' mind. Lévi-Strauss, one of the main supporters of the structuralist conceptualisation, argues that human cultures consist of common features. However these common features are only manifested in the unconscious structure of humans' minds and never in humans' acts of consciousness (Allaire & Firsirotu, 1984). It is however difficult to view culture only as an unconscious process of mind. People tend to assimilate and acculturate with the cultural context that they are involved in and interact with, even if this specific cultural context is absolutely new to them. The more we get involved in a specific cultural context the more possible is to acculturate this cultural context, and behave accordingly. In this case culture is a humans' consciousness process which, in turn, results in a consciousness act of cultural manifestations.

Another school of the ideation conceptualisation of culture is the *Mutual equivalence* school. According to this, culture is a system of standardised cognitive processes through which a general frame of behaviour patterns emerges that rules and determines the interactions among individuals in their social settings (Allaire & Firsirotu, 1984). Therefore culture is an important 'behavioural framework' that shapes and forms the way humans are organised, communicate, act and behave in a specific cultural context. The *Symbolic* (semiotic) school refers to culture as a system of common meanings and symbols. These meanings constitute the materials that people use in order to interpret the social interactions within an ordered system (Allaire & Firsirotu, 1984). Clifford Geertz (1993) was one of the main proponents of the symbolic conceptualisation school. He defines culture as "a historically transmitted pattern of meanings embodied in symbols, a system of inherited conceptions expressed in symbolic forms by means of which people communicate, perpetuate, and develop their knowledge about and attitudes toward life (p. 89)". He proposes that culture is the whole of specific control mechanisms that shape and formulate people's behaviour within a

community (Keesing, 1974). It is through those mechanisms that people define themselves and others, the way they behave, and the way they communicate with each other. According to the symbolic school therefore culture comprises one of the main components of human cognitive processes which gives subsistence to humans' symbols, and shapes the way people interact and communicate with each other.

Culture has been conceptualised through different theoretical and philosophical viewpoints. A lack of a universally accepted definition of culture among scholars has lead to a crisis and triggers criticisms among anthropologists (Papadopoulos, 2009). However we should take into consideration the nature of culture itself, before we raise any criticisms or dispute any of the different concepts and the various definitions of the concept. Culture can be characterised as changeable and multifaceted. It is because of this changeability that its conceptualisation is governed by inconsistency and diversity. This is depicted by Fernando (2003) who states: culture is “something living, dynamic and changing – a flexible system of values and world views that people live by and create and re-create continuously (p. 12)”.

Anything that provides us with a sense of coherence and consistency is culture. Anything, either materialistic, or ideational could be perceived as culture. Culture is the fundamental aspects of our identity that we carry, ‘hold’ and pass from one generation to the other, but it is also what shapes and defines our future behaviour. It is all those cognitive procedures of our minds that help us to understand and interpret realities around us. The meanings and symbols that constitute the conceptions that allow us to perpetuate our knowledge about life. As Segall (1999) states “...cultures are seen as products of past human behaviour and as shapers of future human behaviour. Thus, humans are producers of culture and, at the same time, our behaviour is influenced by it (p.23)”. Culture, in my understanding, and thereafter to this study is not limited in any theoretical conceptualisation, rather its concept lies between the socio-culture and ideational notations of culture. Culture is both a system of ideas that shape our understanding towards life as well as adaptive systems that help humans to relate to their communities, and live within structured societies.

4.3.1 Cultural models and cultural dimensions

Cultural researchers have developed several cultural models and dimensions in an attempt to explain the variability of cultural manifestations across and within diverse cultural contexts. As Matsumoto *et al.*, (1997) states, the “increasing numbers of cross-cultural psychologists

are recognising the importance of conceptualising culture along meaningful dimensions of socio-psychological variability and developing ways to measure these dimensions (pp. 743-744)". There are numerous cultural models, with each of them attempting to identify and nominate specific cultural dimensions. Important work on this area have been conducted by many scholars such as Kluckhohn and Strodtbeck (1961), Hall (1976), Hofstede (1980), and Triandis (1996). The cultural dimensions identified by Hofstede, and later on expanding by Triandis, are widely applied in the cross-cultural literature and are among the most influential cultural dimensions when examining the diversity of cultures (Soares *et al.*, 2007; Rao *et al.*, 2010).

4.3.2 Geert Hofstede's cultural dimensions

Hofstede (2011) defines culture "as the collective programming of the mind that distinguishes the members of one group or category of people from another (p. 3)". He argues, however, that humans' 'mental programs' are different from the computer programs, and therefore do not function in the same way. That is, behavioural patterns are not entirely predetermined by humans' 'mental programs'. Therefore humans have the ability to act, and behave independently of 'the software of their minds'. Humans' programming, he argues, lies in peoples' environment. It starts within the family and it continues throughout other types of social interactions (neighbourhood, work environment, community). Variations on one's social environment result in variations on one's 'mental programs'. Culture therefore is a matrix of attributes, behaviours, traits and psychological characteristics (Lee *et al.*, 2008) which vary from one cultural context to the next.

Hofstede's in a study among 116,000 IBM employees from 70 different countries identified four dimensions of culture. These are:

- Individualism which stresses independency, and loose bonds. Cultures that rank high in individualism are individual-oriented, and promote independence. On the other hand low individualism societies are more collectivistic in nature by promoting group-oriented relationships and inter-dependence. Members of this societies "....from birth onwards are integrated into strong, cohesive in-groups, which throughout people's lifetime continue to protect them in exchange for unquestioning loyalty" (Hofstede, 1991, p. 51)

- Power distance refers to the existed inequalities in relation to hierocracy and authority. Societies with low power distance emphasise equality and promote equal opportunities. High power distance societies emphasise inequalities “These societies are more likely to follow a system that does not allow significant upward mobility of its citizens” (Geng, 2010, p. 221).
- Uncertainty avoidance. This cultural dimension refers to the extent of ambiguity and uncertainty in societies. Low uncertainty avoidance indicates societies that are more favourable to changes, while high uncertainty avoidance indicates more conservative societies. Masculinity refers to the extent that ‘masculine’ or ‘feminine’ characteristics predominate. High masculinity societies promote competitiveness and success, while low ‘masculine’ societies promote harmonic relationships, and high quality of life.

Bond (1987) conducted a study (The Chinese Culture Connection) among 1,528 Chinese students in 22 different countries. His work revealed an additional cultural dimension named Confucian Work Dynamic. Later on, Hofstede adapted the fifth dimension in his model, which in 2001 he renamed as the Long-Term Orientation cultural dimension (Wu, 2006). The Long-term Orientation cultural dimension refers to a society’s superiority than truth. Societies with short-time orientation believe that truth is significant, and people within these societies are quite traditional, normative in their thinking, and focused on achieving quick results (Hofstede, 2011).

Two new dimensions were found by the sociologist Michael Minkov (2007) who wished to replicate Hofstede’s cultural dimensions by analysing data from the World Values Survey (WVS) database. He initially identified three new dimensions, named Exclusionism versus Universalism, Indulgence versus Restrain and Monumentalism versus Flexumity. The Exclusionism/Universalism dimension was found to correlate with the Individualism/Collectivism cultural dimension, yet the other two dimensions were new. In 2010, Hofstede, adopted the Indulgence/Restrain cultural dimension in his model. This dimension refers to peoples’ satisfaction and regulations within cultures. Gratification of basic and natural human needs is relatively free within indulgence cultures, while suppression of humans’ gratification through strict regulations is dominant within restrain cultures (Minkov, 2007; Hofstede, 2011). The continuous establishment of new cultural dimensions may indicate that cultures are not static over time, but changeable. However these cultural

dimensions focus on the cultural level of cultural subscriptions and not the individual level. Triandis and colleagues (1998) developed the VHIC cultural model that focuses on explaining individual levels of specific cultural subscriptions across and within cultures. The model has been adopted in this study and is discussed later in section 4.2.3.

Hofstede's cultural dimensions attracted much research attention, with the individualism/collectivism (I/C) cultural dimension to predominate cross- and within cultural research. Yet his work was also the subject of criticism. For example, scholars argue that Hofstede's dimensions were developed based on empirical, and not theoretical, evidence (Albers-Miller & Gelb, 1996; Soares *et al.*, 2007) which undermines the concept's conceptualisation. They also characterise Hofstede's work as outdated (Jones, 2007; El-Azez Safi, 2010) since its implementation took place over 20 years ago, and therefore problematic considering the rapid change of the socio-cultural systems. Hofstede, however, argues that while culture does change, it will not change overnight (Hofstede, 1998). Hofstede and Usunier (1999) agrees stating that "national cultural value systems are quite stable over time; For example countries that were once part of the Roman Empire are still sharing some common value elements today, as opposed to countries without a Roman cultural heritage (p. 120)" (seen in Daryanto, 2013).

Another criticism associated with Hofstede's work is the process of his data analysis. Hofstede aggregated the data into group levels and disregarded the individual levels of cultural subscriptions (Fernandez *et al.*, 1997; McSweeney, 2002). This is a significant limitation since there is a substantive need to examine cultural dimensions at the individual levels rather than the group levels (Yamada & Singelis, 1999). McSweeney (2002) goes further to state that Hofstede's cultural model is based on assumptions which cannot be considered as entirely true, and Jones (2007) and El-Azez Safi (2010) argue that surveys are not the most effective method when cultural disparity is measured.

Hofstede's model and thus cultural dimensions have been criticised by a number of scholars and for various reasons. However his work is until today widely applied and adopted in many cross-cultural studies. As Soares *et al.*, states (2007) "the usefulness of the concept of culture to explain cultural differences depends on being able to unpack it and identify its components; as culture is too global a concept to be meaningful as an explanatory variable (p.

279)”. Hofstede’s cultural dimensions have advanced cross-cultural researches’ knowledge about the various types of characteristics within the same and/or different cultural contexts.

4.3.3 The I/C cultural dimensions

One of the most important and useful constructs that have been emerged within the social psychology research is the I/C cultural dimension. The latter dimension has been widely used in explaining and describing cultural differentiations (Vandello & Cohen, 1999). In contemporary times the I/C cultural dimension was revived through the work of Hofstede.

The I/C paradigm categorises cultures into individualistic and collectivistic ones. People from individualistic cultures prioritise their individual goals, autonomy and dependency, while their behaviour is ruled by their own attitudes, and not by in-group norms and values. On the other hand people in collectivistic cultures are highly interdependent, prioritise in-group goals over personal goals, while their behaviour aligns and follows in-group values and norms (Triandis, 2001; Lefebvre & Franke, 2013) (table 3). According to McLeod (2014) countries which belong to developed Westernised world are more likely to be individualistic, while developing Eastern countries are more likely to be collectivistic. The I/C cultural model is one of the key dimensions in differentiating and categorising cultures, and individual cultural subscriptions, between and across cultures.

In 1989, Triandis replicated some of Hofstede’s results, yet his analysis revealed a distinction between the individual/personality level and the cultural level. Cultural dimensions of collectivism and individualism are opposite to each other (Hofstede, 1980) when data are collected and compared across cultures. However collectivism and individualism are orthogonal to each other when data is compared within cultures at the individual level (Triandis & Suh, 2002). That is, “individuals high in individualism are not necessarily low in collectivism and vice versa” (Kimmelmeier *et al.*, 2003, p. 305). These variations resulted to the terms ‘allocentrics’ and ‘idiocentrics’ (Suh *et al.*, 2009). Allocentrics and idiocentrics are personality variables which correspond to the collectivistic and individualistic cultural dimensions respectively.

Triandis (2011) argues that there are allocentrics and idiocentrics in both individualistic and collectivistic cultures, however there is a higher number of allocentrics in individualistic

cultures, and a higher number of idiocentrics in collectivistic ones. Similar to the I/C model allocentrics are inter-dependent, behave according to their in-groups values, and join communes and associations, while idiocentrics are independent, competitive and behave according to their own attitudes. The distinction of individual and cultural level has advanced cross-cultural research and the way researchers examine culturally constructed psychosocial phenomena.

Triandis also proposes several other indicators that differentiate cultures. One of them is known as ‘ecology’. According to Triandis ecology distinguishes cultures according to their level of power and geographic area. He argues that societies who are geographically separated and/or isolated are ‘tight’. These societies are more collectivistic, and their members are characterised by high levels of inter-dependence. Societies who are ‘tight’ have clear norms, values and ideas of what behaviours are socially acceptable and socially unacceptable. Therefore people within these societies strive to behave according to the socially acceptable norms in order to maintain the cohesion between in-groups. On the opposite end of the continuum are ‘loose’ societies or cultures. Within these societies people are highly independent, and any potential deviance of the norms can be viewed with tolerance.

Table 3: Individualist/Collectivistic cultural orientations

Individualistic Cultures	Collectivistic Culture
<ul style="list-style-type: none"> • Individual-centred • Priority to individual goals • Independence • Less attention to norms • Behaviour based on attitudes rather in-group norms 	<ul style="list-style-type: none"> • In-group-oriented • Priority to in-group goals • Interdependence & Connectedness • Accordance with the norms • Behaviour based on in-groups values and norms

Hofstede (1991) also discusses individualism and collectivism cultural dimensions. According to him, “individualism stands for a society in which the ties between individuals are loose; everyone is expected to look after himself or herself and his or her immediate family only” and “collectivism stands for a society in which people from birth onwards are

integrated into strong, cohesive in-groups, which throughout people's lifetime continue to protect them in exchange for unquestioning loyalty" (pp. 260-261).

Hofstede also argues that people within the individualistic cultures favour challenges, freedom, and value their personal time. With regard to their family relationships, they respect honesty and truth, maintain self-respect, and use 'guilt' to achieve their goals. Their societies prioritise the individual socio-economic interests, value privacy and freedom, emphasise autonomy and self-realisation, limit the influence of the power of the state to the economy, and emphasise the power of the voters. In contrast, Hofstede argues that people belonging to collectivistic oriented cultures appreciate good physical conditions, skills, and they value training at work. With regard to their family relationships, people from collectivistic cultures value harmony, use 'shame' to achieve their goals, prefer silence instead of speech, and finally emphasise the maintenance of "good face". Their societies are ruled by collectivistic laws, emphasise the group social-economic interests, while the state dominates economy, and limits the freedom of the press.

The constructs of I/C have widely been used in explaining psychological impacts of culture over the last 20 years (Oyserman *et al.*, 2002; Shavitt *et al.*, 2010; Du *et al.*, 2015). However, scholars have criticised the I/C dimensions to be very broad and multifaceted in nature, and as such it fails to provide useful insights into cultural variations (Oyserman *et al.*, 2002; Shavitt *et al.*, 2010); which is one of its key limitations. To address this limitation, Triandis (1996) developed the Vertical Horizontal Individualism Collectivism cultural model (VHIC). Triandis (1996) argues that variations within the I/C dimensions can exist and coexist within a single culture, opposed to Hofstede who believes that I/C dimensions are two opposite ends of a continuum (Hsu & Barker, 2013). The VHIC model explains these variations within individualistic and collectivistic cultures, and has been influential to this study.

4.3.3.1 The VHIC cultural dimensions

Triandis suggests that I/C should be viewed and examined as "polythetic constructs", and proposes four typologies within the I/C cultural dimensions. These four typologies explain cultural differentiations at the individual levels and are: the vertical individualism (VI), horizontal individualism (HI), vertical collectivism (VC) and horizontal collectivism (HC). The vertical typologies emphasize hierocracy, while the horizontal typologies emphasize

equality (Triandis & Gelafand, 1998; Ladhari *et al.*, 2015). Therefore some cultures and societies are “hierarchical-oriented”, while others are “equality-oriented”. The four categories that are nested within the I/C dimensions are based on observations that reveal cultural differentiations between and across similar cultural contexts. For example, American or British individualism is different compared to Danish or Swedish individualism, while Korean or Japanese collectivism differs from the Israel kibbutz one (Shavitt *et al.*, 2010). The VHIC cultural model has advanced our understanding about the nature of culture, yet the model fails to capture all the existing cultural differentiations across and within cultures neither at the cultural level nor at the individual level.

People within VI societies (e.g. England) generally aim to improve their social status and distinguish themselves from others. Competition, achievement, power, and standing out are key constructs. On the other hand societies that subscribe to HI (e.g. Denmark) avoid status differentiation, and are concerned with achieving status equality (Zhang *et al.*, 2011; Ladhari *et al.*, 2015). A study by Nelson and Shavitt (2002) examined such notions. The authors used a mixed method approach to examine values differentiations among Danish (82 students) and Americans (152 students) participants. Both methods revealed that Americans and Danish were individualistically oriented, however the findings showed variations within the individualism cultural subscriptions. Specifically, that Americans were VI-oriented, while Danish were HI-oriented. Americans gave more priority to achievement goals, and evaluated the achievement values higher than their Danish counterparts.

People within VC societies (e.g. South Korea) aim to enhance harmony and interconnectedness with their in-groups. They prefer to sacrifice their personal goals for the goals of their in-groups, and to maintain cohesion by complying with the authorities. In HC societies or cultural contexts (e.g. Israel Kibbutz), people aim to maintain interconnectedness under the context of a more equality-oriented framework (Shavitt *et al.*, 2010; Landhari *et al.*, 2015). In 2001, Chiou examined the strength of the four typologies (VC, VI, HC, and HI) among Taiwanese, American, and Argentinean college students. The study’s findings revealed that American were less vertically collectivistic than the Taiwanese and Argentinean students, while the Taiwanese students were more vertically individualistic than the Argentineans students. The study replicated previous findings, and supported the four patterns of individualism and collectivism.

Oppenheimer (2004) examined individual levels of I/C and VHIC dimensions in a Dutch sample of secondary school students (n=245) and psychology students (n=268). Results revealed that the Dutch sample value horizontal (neither collectivism nor individualism) dimensions while VI and VC dimensions are not presented. The findings replicate a) the existence of cultural variations within societies, however this time in the individual level and not in the cultural level and b) the differentiations between HI and HC cultural orientations. The study used a representative sample of the population, and thus generalisation of the findings can be applied.

The VHIC model also aligns with the sociality model proposed by Fiske (1992). That is “communal sharing” taps into collectivism, “authority ranking” into vertical relationships, “equality matching” into horizontal patterns, and “market pricing” into individualism (Triandis & Gerflend 1998). Vodosek (2009) examined relational models and cultural orientations among 465 members of chemistry groups in 24 U.S universities. The findings reveal correlations between authority, communal sharing, and equality match with vertical, collectivism, and horizontal collectivism orientations respectively. The significant role not only of the I/C dimensions but also of the four typologies (VC, VI, HC, and HI) was highlighted (seen in Shavitt *et al.*, 2010). Thus the vertical-horizontal cultural dimensions are significant constructs in examining variations within the individualism and collectivism orientations.

Vargas and Kimmelmeir (2013) using a meta-analytic approach examined cultural differences among four groups in the US (African, Asian, Latino, and European Americans). They found that European Americans were more vertically individualistic compared to African Americans and Latino Americans, while African Americans were more horizontally individualistic. The findings revealed horizontal and vertical cultural differences, yet there was an overall cultural consistency among groups. The authors argued that young Americans share similar cultural values compared to 15 years ago because of the increasing cultural exchange.

Landhari *et al.*, (2015) used the VHIC model and examined culture homogeneity and its stability among 720 participants from three countries (207 in Canada, 263 in Japan, and 250 in Morocco). They found that all countries are high in HC. However, Morocco and Japan were higher in VI, while Canada was high in both HC and HI. This indicates that different cultural values can coexist within one dominant culture. Cross-group comparisons revealed

that Moroccan scored higher in the HC scale compared to Canadians and Japanese counterparts, while both Moroccans and Japanese were higher in VC than Canadians. On HI Canadians scored higher compared to Japanese and Moroccans. Finally, Moroccans were higher than Canadians and Japanese, and Japanese were higher than Canadians in VI. The authors concluded that cultures are neither homogeneous nor stable over time.

The VHIC model has advanced our understanding on cultural differentiations across and within cultural contexts (table 4). Some cultures seem to be “equally-oriented”, while others “hierarchy-oriented”. These variations are present both at the cultural level and individual level. Therefore people subscribing to VI are more strongly independent, competitive and stress status differentiation, while people valuing HI are more independent and competitive, yet they also value equality. In VC cultures, people prioritise harmony, and submission to the authorities, while people valuing HC wish harmony through equality. Shavitt *et al.*, (2010) highlight the importance of the VHIC model by stating that “although the broad definition of collectivism has focused on interdependence and the maintenance of social relationships, several studies suggest that it is people with an HC orientation who are particularly oriented toward sociability and are motivated to maintain benevolent relationships. Similarly, although independence and a focus upon self-direction and uniqueness have been key to the definition of individualism, it appears that it is those with an HI orientation who are especially motivated to maintain their self-image as being separate from others and are capable of self-reliance (p. 11)”. The four typology models of the I/C dimensions is key for this study.

Table 4: VHIC cultural dimensions

VI	HI	VC	HC
<ul style="list-style-type: none"> • Strongly independent, • Competitive • Stress status differentiation 	<ul style="list-style-type: none"> • Independent • Competitive • Value equality 	<ul style="list-style-type: none"> • Prioritise harmony • Submission to the authorities 	<ul style="list-style-type: none"> • Harmony through equality

4.4 Rationale for adopting the VHIC model

The I/C model, as stated earlier, is one of the most widely used models in examining culturally constructed psychosocial phenomena. On the other hand the VHIC model has widely been used in examining cultural differentiations of psychosocial phenomena both at the cultural and individual level. For this study culture is viewed as both an objective and subjective construct by giving equal weight to both its materialistic and non-materialistic nature (values, beliefs etc.). The former approach of culture aligns with the I/C and VHIC models since both of them examine cultural and individual subscriptions according to specific cultural values, beliefs and behaviours, and is the key reason of using it in this study.

This study examines the inter-relationships of self-stigma, loneliness and culture, while explores experiences of loneliness and self-stigma in the concept of participants' culture. Therefore, this study aims to examine prevalence and experiences of self-stigma and loneliness at the individual level. This is important given the strong indications in the literature that cultural subscriptions both at the cultural and individual level influence the way stigma and loneliness is experienced (chapter 5). The I/C paradigm and the VHIC model seem to adequately meet the aim of this study.

4.5 Summary

Two main schools of thought have monopolised discussions on the concept of culture, over time. These are the socio-cultural (materialistic) and ideational. The socio-cultural (materialistic) school views culture as a socio-cultural system which is interrelated and interconnected to human materials, while the ideational views culture as a non-material 'entity' that emphasises humans' ideas. The numerous existing definitions of the concept also highlight culture's complex and multi-faceted nature. In this study, culture is the 'memory' of past visible and invisible components that define people's current and future behaviour, and can be viewed in cultural dimensions. That is, humans' values, beliefs and behaviours develop specific cultural dimensions, while specific cultural dimensions influence humans' beliefs, and behaviours. Therefore, cultures can be both objectively and subjectively examined. The latter aligns with the I/C and the HVIC model since both models prioritise humans' values, beliefs and behaviours and their relationships to cultural values.

Cultures are multidimensional and complex constructs. Therefore researchers have developed several cultural models and dimensions so that to address this complexity. One such widely

applied and used cultural model is the I/C paradigm which revived through Hofstede's work, and popularised through Triandis. However the need in examining cultural differences both at the cultural and individual level resulted in the development of the VHIC model. The VHIC model has also been widely used in explaining cultural differentiations of psychosocial phenomena. This model is key for this study since it aims to examine within-cultural variations of self-stigma and loneliness among older adults experiencing mental health problems in nursing homes.

Chapter 5 Culture, self-stigma and loneliness: a literature review

Culture plays a key role on the way people experience and interpret psychosocial phenomena. This is one key aim for this study since it explores the role of culture upon levels and experiences of loneliness and self-stigma among older adults with mental health problems in nursing homes. This chapter therefore provides a review of cross-cultural and within-cultural literature on self-stigma and loneliness.

5.1 Cultural variations of self-stigma

Coker (2005) argues that the way stigma is formed depends upon cultural norms. That is, different cultural norms and values result in variations on levels and experiences of stigma. Many other scholars have also highlighted the important role of culture, both at the cultural level and individual level, when examining stigma (Tzouvara & Papadopoulos, 2014; Hanafiah & Van Bortel, 2015). However our knowledge about self-stigma variations comes mainly from studies within the American cultural context which constitutes comparisons to other cultural contexts problematic. Also the empirical data regarding cultural variations on self-stigma are limited with the majority of studies to addressing public stigma among ethnic groups and cross-national populations.

Anglin *et al.*, (2006) in a national study, aimed to examine racial differences on public stigma towards people with schizophrenia and depression among a representative sample of 81 African Americans and 590 Caucasians. The results indicated that African Americans compared to Caucasians were more likely to stigmatise people with mental illness by considering them dangerous. The results remained significant even when controlling for age, income, education, political views and religion. However, African Americans were less likely to think the mentally ill as violent and less likely to support the punishment of the mentally ill due to violent acts (Anglin *et al.*, 2006). Yang *et al.*, (2013) developed a stigma framework to illustrate the role of culture in threat perception and stigma by examining a national sample of 56 Chinese Americans and 589 European Americans. The authors used a vignette experiment of attitudes and stigma towards mental illness. They found that Chinese Americans were more social restricted and social distant towards people experiencing mental illness compared to their European American counterparts. The Chinese sample had comparatively higher stigma outcomes, even when controlling for socio-demographic variables. One of the limitations of this study was that participants belonging to the Chinese participants were

sampled through a non-randomised technique. Thus it is unclear whether or not the findings apply to the general population. However, the above findings indicate that cultural variations on public stigma do exist. If this is the case, then cultural variations on self-stigma may also exist, since public stigma and self-stigma indicate conceptual similarities (Corrigan & Watson, 2002).

Empirical evidence on cultural variations of self-stigma is limited. However, one study by Brohan *et al.*, (2010) provides useful insights. The authors examined levels of self-stigma, empowerment and perceived discrimination among people diagnosed with schizophrenia residing in 14 European countries (Belgium, Bulgaria, Croatia, the Czech Republic, Estonia, Finland, France, Greece, Italy, Lithuania, Malta, Poland, Romania, Russia, Slovenia, Spain, Sweden, Turkey and Ukraine). One thousand two hundred twenty nine individuals belonging to non-governmental mental health organisations were sampled through a postal questionnaire survey. The authors utilised the Internalised Mental Illness Scale in assessing participants' levels of self-stigma. Four self-stigma categories were utilised: <2 minimal stigma, 2–2.5 low stigma, 2.5–3 moderate stigma and, 3+ high stigma. Overall, the levels of self-stigma were moderate-high among the individuals from all the above European countries. However, the findings did also reveal cross-cultural variations of self-stigma levels. For example, in Lithuania the mean score of self-stigma was comparatively lower (mean=2.34, SD=0.48), while in Greece the levels of self-stigma were higher (mean=2.97, SD=0.49). Lithuania, according to The Hofstede Centre (2014), is considered to be an individualistic-oriented country whereas Greece is described as a collectivist-oriented one. This indicates the possibility of individualism potentially correlating with lower self-stigma and collectivism with higher self-stigma.

Conner *et al.*, (2010) through a telephone questionnaire survey, examined the relationships between stigma (both public and self-stigma), race, and treatment seeking attitudes and behaviours among a representative sample of 120 African and 128 White American older adults (aged 60 – 93 years) suffering from depression. Levels of internalised stigma were assessed through the Internalised Mental illness Scale. Bivariate analysis of the results indicated that older African Americans internalised significantly higher levels of stigma compared to their White American counterparts. However the results did not reveal a significant variation on public stigma among the two groups. Overall, the sample as a whole was more likely to be vulnerable to public stigma compared to self-stigma. Their analysis

also showed a significantly positive relationship between internalised stigma and intentions of seeking treatment, and a significantly negative relationship between internalised stigma and attitudes towards seeking mental health services. That is, older adults independently of racial identification with higher internalised stigma were more likely to hold negative attitudes towards seeking mental health services, and they were less likely to intend to seek treatment. One limitation of the study is concerned with the identification of the participants. Participants in this study were self-assessed for depression, however as the authors of this study stated “ without assessing perceived need for treatment it is difficult to know whether individuals surveyed actually viewed themselves as having depression, which is impacted to study results (p.11)”. Although the study examined racial differences of internalised stigma, public stigma and attitudes of seeking mental health services among older adults, it did not aim to address cultural variations of internalised stigma among older adults at the individual level. However the findings of the above study provide further indication of the potential variations of levels of self-stigma among this age-group.

Cheng *et al.* (2013), in a questionnaire survey, explored the effects of psychological distress and psychocultural variables on self-stigma, seeking treatment and perceived discrimination among ethnic and racial minority college students. Levels of self-stigma towards help seeking were assessed through the Self-Stigma of Seeking Psychological Help scale. The sample of the study consisted of 260 African American, 166 Asian American, and 183 Latino American students aged 18 to 55 years old. They found that ethnicity was significantly and negatively associated with self-stigma among African Americans and Latino Americans participants, but not Asian Americans. They also found that higher ethnic identity associated with lower self-stigma towards seeking psychological help among African American participants. The authors argued that perceiving oneself as a member of an ethnic group provides psychological security, and therefore reduces stigma for seeking psychological help. Although the study aimed to explore self-stigma towards psychological help and not levels of mental illness self-stigma under its broader context, it still provides further insight into the cultural variations of self-stigmatisation. However we should view any conclusions with caution, since mental illness self-stigma has not been directly assessed. Another limitation of the study was that participants were sampled based on their ethnicity and not their cultural orientation and/or cultural values.

Bailey *et al.*, (2014) in a systematic review of the literature aimed to examine the sociocultural factors that may influence the diagnosis and management of attention deficit/hyperactivity disorder (ADHD) among African Americans and Hispanics in primary care in the US. The authors identified four main factors that influence diagnosis and management of ADHD among African Americans and Hispanics. These are: access to medical services, insurance, cultural attitudes, and stigmatisation and discrimination. More specifically, more than half of parents with children suffering from ADHD stated fear that their children will be labelled by the diagnosis as one key reason for not seeking treatment, while 36% of African American and 19% of Hispanic parents reported that race could affect the care provided to their children. The authors also stressed the key role of physicians in primary care when dealing with patients from minority groups suffering from ADHD.

Chen *et al.*, (2015) examined beliefs about mental illness among 190 depressed Chinese Americans immigrants who were seeking primary care in the US. The authors found that stigma was high among this population. More specifically, 40% of them were reluctant to disclose their illness to anyone, while 5.8% of them would conceal their illness from most people. In addition, 32.6% of participants had insight into their mental illness and were able to identify the name of their illness (e.g. depression, mental disorder), yet only 8.9% of them would use the term when discussing it with others. The authors concluded that “the tremendous degree of stigma endorsed by participants and their reluctance to share the diagnostic label with others (which was not seen in the earlier study) suggest that providers should be sensitive to a heightened need for privacy and discretion in discussing the diagnosis (p. 22)”.

The literature suggests that there are cultural variations on mental illness stigma. However, empirical findings come mainly from studies among Asian Americans and African Americans. There is, therefore, a need for further investigation on the relationship between mental illness self-stigma and cultural values among other cultural groups (Abdullah & Brown, 2011). This study, therefore, is aiming to provide insight to this body of knowledge.

5.2 Cultural variations of loneliness

Loneliness has been found to reduce older adults' quality of life by causing decreased life satisfaction, increased utilisation of health care services and increased risks of mental health

problems (Golden *et al.*, 2009). The interactionist theory adopted in this study refers to two types of loneliness: social loneliness and emotional loneliness (Weiss 1973; de Jong Gierveld, 1998) which are inevitably influenced by cultural context (Lou & Ng, 2012). Therefore differentiations in cultural and societal values may result in differences in the way people build, maintain and shape their emotional and social relationships. Loneliness may therefore be the ‘product’ of the absence and/or deficiencies to social and emotional relationships, which are affected by cultural values and norms. Rokach *et al.*, (2004) argued that “the difference between cultures and the ways people's social relations are organized within them will result in cross-cultural variations (p. 125)” of loneliness. Empirical data coming from cross-cultural loneliness literature add weight to this proposition. However our knowledge is limited in relation to within-cultural variations of loneliness among older adults with mental illness residing in nursing homes.

Early studies investigating cross-cultural variations on loneliness highlight the importance of examining loneliness in relation to one’s cultural context. For example, in 2002, Rokach aimed to identify the techniques that older adults in North America and Portugal use to cope with loneliness. One hundred forty one older adults (age range = 60-83 years) participated in a questionnaire survey. The 82-items of the questionnaire asked questions about reflection and acceptance, self-development and understanding, social support network, distancing and denial, and religion and faith. The findings indicated that Canadian older adults scored significantly higher on the reflection and acceptance, distancing and denial, and religion and faith items compared to Portuguese older adults. Therefore, the older adults in North America used techniques of self-reflection and self-search in order to cope with loneliness compared to Portuguese counterparts. Also the North-American older adults were more likely to deny suffering from loneliness, and to engage in religious practices in alleviating loneliness, while they were more willing to distance themselves from social connections. However the older adults who participated in this study did not constitute representative samples of their target population. Despite this, the study did identify cultural differences in coping with loneliness. Given this, there may also be cultural variations in the way older adults understand and experience loneliness. This study aims to investigate this notion.

Rokach and Neto (2005) examined how age and culture influence perceptions on the causes and experiences of loneliness. The 82-items loneliness questionnaire was administered to 1347 Canadian and Portuguese participants across four age groups (13-18, 19-30, 31-59 and

60-83 years). Overall the findings indicated that loneliness is present across the life span, and that culture has a significant effect on peoples' perceptions of loneliness. More specifically, Canadian participants across all age groups were significantly more likely to experience loneliness compared to their Portuguese counterparts. The authors argued that the individualism cultural orientation of the Canadian group partially explains the higher levels of loneliness among them. The latter helps build the theoretical basis of this study. The findings also revealed that the elderly were significantly more likely to perceive loneliness as a result of relocation, separation and social marginalisation. Therefore the elderly perceive themselves more vulnerable to loneliness both because of loss of loved ones and/or intimacy relationships, and because of chronic health problems (including mental illness) causing social rejection. One limitation of the study was that the sample was not representative of the target population, so claims for findings generalisations should be made with caution. In addition, cultural differentiations between Canadians and Portuguese were not directly assessed. However, the study provides evidence on the cultural variations of loneliness.

In 2005, DiTommaso and colleagues examined the universality of loneliness and attachment in family, romantic and social relationships among 223 Canadian University students and Chinese visiting students aged from 18-45 years old. The questionnaire consisted of the Inventory of Parent and Peer Attachment scale and the Emotional and Social Loneliness Scale. The results of the study revealed that Chinese students endured significantly higher levels of family, romantic, and social loneliness, and lower levels of attachment security for both peer and romantic relationships. Specifically Chinese males were scored significantly higher to family loneliness compared to their male Canadians counterparts. On the other hand Chinese females reported no significant differences on family loneliness compared to their female counterparts. This study also provides useful findings about within-cultural variations on loneliness. However the target group of the above study was University students and thus the findings cannot be applicable to older adults. The authors of the study also argued that inter-cultural comparisons and examination of loneliness at the individual level of cultural values is needed. The latter further underlines the need for the implementation of this study.

One year later Stevens and Westerhof (2006) examined the availability of support, companionship, and negative relational experiences in various types of relationships for married men and women aged 40 to 85 years. A primary aim of the study was to identify and compare the relationships between gender, social networks and their mechanisms and

loneliness among German and Dutch participants. The sample was comprised of 3,119 randomly selected German participants and 727 Dutch participants who were married and cohabiting. The sample was identified through the German Aging Survey and the Dutch Aging Survey respectively. Loneliness was measured with a Dutch 11-items scale. The findings reported no significant differences on levels of loneliness among the two groups. One possible explanation is because the above groups share similar cultural values. The latter highlights the need for more research on within-cultural variations of loneliness. The findings of the study drew upon a representative sample of German and Dutch respondents, and therefore they may depict an accurate picture of loneliness. However there was an over-representation of people who were healthier and aged 70 to 85 years old, and the study suffered from a low response rate (48%).

Chalise *et al.*, (2010) examined social support and the predictors of loneliness among older adults from two Nepalese ethnic groups (Chhetri: n=137; Newar: n= 195) in a cross-sectional survey. The UCLA loneliness scale was utilised. Although the findings did not reveal any significant differences among participants in relation to social support and reductions of loneliness, there was a significant difference on the ‘children living apart’ social support factor between the two groups. Specifically, sources of social support from children living apart was associated with significant reductions in loneliness in the Newar elderly but no such finding was identified in the Chhetri elderly. The authors stated that “there is a high degree of cross-cultural invariance in the predictor sources of social support on loneliness among the two Nepalese castes/ethnicities older adults (p. 115)”. However, no generalisations can be made since participants were sampled from one convenient ward of Kathmandu metropolis. Despite this and other limitations, the study indicates the potential inter-cultural variations of loneliness among older adults by highlighting the need for further investigation on the topic.

Another study by Lou and Ng (2012) examined what factors increase resilience towards loneliness among older adults. One-to-one semi-structured interviews were conducted with 13 community dwelling older adults living alone in China. Their findings revealed that Chinese older adults endorsed a family-oriented and relationship-focused resilience coping mechanism model. The authors argued that the findings come in line with the Chinese culture which is collectivistic oriented and thus family inter-connectedness and in-group harmony serves as coping mechanisms to loneliness even when they live alone.

In 1990, Jylhä and Jokela examined patterns of loneliness among elderly residing in six European regions: Tampere (Finland), West Berlin (German), Tuscany & West Amiata (Italy), Greece (21 small rural towns and villages), and Belgrade (Yugoslavia). They investigated if the differences on loneliness could be explained by the cultural differentiations on social relations and life-situations among the elderly residing in Greece and Tampere. The data were sourced through The Eleven Country Study on Health Care of the Elderly which was implemented in 1979-80. One single loneliness question was used. The findings revealed an increase in loneliness when moving from the North to the South, although there was an increase on social interactions with friends and family and a decrease in living alone circumstances. Elderly residing in Greece were found to be lonelier than elderly residing in Tampere. One limitation of this study is that one single loneliness question was used. The one loneliness question assumes a generic and universal understanding of the concept of loneliness.

Fokkema *et al*'s study (2012) gives more weight to the Jylhä and Jokela (1990) findings. The authors examined loneliness among older adults age 50 years old and older. Data were used from the SHARE surveys encompassing participants from Austria, Belgium, the Czech Republic, Denmark, France, Germany, Greece, Ireland, Italy, the Netherlands, Poland, Spain, Sweden, and Switzerland (n= 12,248). One single loneliness question was used. The authors found results similar to Jylhä and Jokela (1990) in that older adults living in Southern and Central European countries were more likely to feel lonely than their Northern and Western counterparts. Therefore cultural variation of loneliness seems to exist across- and within cultures.

Lykes and Kemmelmeier's (2014) assessed levels of loneliness by using data from 12 (1992 Eurobarometer; n= 3,902) and 22 (2006 European Social Survey; n= 38,867) European societies respectively. They found that prevalence of loneliness is higher among participants living in collectivistic oriented cultures compared to individualistic oriented ones. In collectivistic societies loneliness was linked with lack of family interactions compared to individualistic societies where loneliness was closely linked with the absence of friends and/or confidants. Therefore collectivistic oriented participants pay much attention to family relationships, while individualistic oriented participants value more the relationships with friends and confidants. The findings of this study come in line with previous research in loneliness. That is, traditionally collectivistic elderly are more likely to experience loneliness

compared to individualistic oriented ones. However we should not neglect how inter-cultural variations explain loneliness, and particularly how individual levels of cultural values explain and inter-relate with loneliness.

de Jong Gierveld *et al.*, (2015) aimed to compare levels of loneliness among immigrants and native-born Canadian older adults. They used data from the Canadian Social Survey Cycle 22 (N= 3,692), and the de Jong Gierveld loneliness scale in assessing loneliness. They found that, overall, immigrants experience significantly higher levels of loneliness compared to their native-born counterparts. The findings also revealed differences in the levels of loneliness among immigrant groups and native-born Canadians older adults. More specifically, immigrants from Europe, but French and British ethnic origins, had higher loneliness compared to Canadians born older adults, while immigrants from non-European ethnic origins, reported the highest levels of loneliness, and scored significantly higher compared to those born in Canada. Also older adults who had different native language/culture were significantly lonelier compared to those with similar language/culture. The authors also found that belongingness, participation in local communities, composition of social networks, and cultural background are key factors in explaining loneliness among older immigrants.

The literature review indicates cross-cultural variations on loneliness among older adults. The findings of the above studies give weight to the proposition that loneliness, despite its subjectivity, is experienced differently from one cultural context to the next. The way, therefore, relationships are shaped within the members of a society cause variations and differentiations on the levels and experiences of loneliness. The findings reveal that collectivistic-oriented individuals are lonelier compared to individualistic-oriented ones. In spite of the study limitations, there is an evidence base for the notion that cultural values impact upon the experience and degree of loneliness. Cultural values at the individual level may also influence feeling of loneliness. This study examined this proposition.

5.3 Summary

Cross-cultural research on stigma advanced our knowledge on levels of stigma among different cultural contexts. For example, a vast number of studies reveal that collectivistic-oriented people are more likely to stigmatise compared to individualistic oriented ones. This is not surprising since people belonging to collectivistic societies value in-group harmony and inter-connectedness, thus any characteristic/or condition (for example mental illness) which

will potentially 'spoil' this harmony and inter-connectedness would be viewed as undesired and would probably be stigmatised. Cross-cultural research, although widely implemented on examining public stigma, is limited regarding levels of self-stigma. Also our knowledge is insufficient about within-cultural examinations of self-stigma. However, studies reveal that self-stigma is higher among collectivistic-oriented cultures.

On the other hand cross-cultural research regarding loneliness among older adults is well-implemented. The literature on cultural variations of loneliness reveals that collectivistic-oriented older adults are lonelier than individualistic-oriented ones. However studies assessing within-cultural variations of loneliness are limited.

Chapter 6 Methodology

6.1 Introduction

This chapter discusses the research design of this study. This includes the rationale behind the implementation of an explanatory sequential mixed-method design by drawing upon the past self-stigma, loneliness and cultural literature, a presentation of the advantages and disadvantages of the implemented research design, and a description of how the utilised research design aligns with the researcher's epistemological stance. A discussion of the epistemological underpinning of this study is also presented.

6.2 Study design

This study adopts an explanatory sequential mixed-method design with two distinct phases: a) Phase 1: quantitative questionnaire survey, and b) Phase 2: interpretive phenomenological approach. A mixed method design combines qualitative and quantitative techniques, methods and approaches aiming at the extensive exploration of a phenomenon (Bryman, 2012).

The qualitative data collection and analysis followed the quantitative in the sequence (please see figure 9). The qualitative findings therefore aimed to further explain the quantitative results with the two phases connecting in the study's intermediate stage (Punch, 2009). This led to several advantages. Firstly, the quantitative phase usefully allowed for eligible participants to be identified and participate in the qualitative phase of this study. Secondly, the quantitative phase helped in forming relationships of trust or familiarity between participant and researcher that increased the likelihood of response rates during the qualitative phase. Third, the quantitative phase was able to evidence the existence, type and severity of self-stigma and loneliness in this setting and thus both justified the need for a follow-up qualitative investigation and helped in determining the focus and structure of the qualitative interview schedule.

The implementation of mixed method approaches can be traced back to the psychologists Campbell and Fiske (1959) who used multiple quantitative methods in investigating research inquiries, and later on to Jick (1979) who adopted mixed method approaches in triangulating and converging various qualitative and quantitative data sources (Cook, 2013). The incorporation of mixed method approaches among different disciplines led to 'the development of a distinct methodology of inquiry' (Creswell *et al.*, 2007; Creswell, 2009a).

These ‘interactive processes’ influenced the discussions over the issue of combining quantitative and qualitative methods in one single study which resulted to the growth of the paradigm debate in the 1970’s and 1980’s. The paradigm debate pertains to the notions that the combination of quantitative and qualitative methods is unachievable and should not be performed, since each method belongs to and is formatted by distinct and different ontological and epistemological paradigms (Smith, 1983).

In more recent years, however, mixed method approaches have gained more weight within the scientific world. *The Handbook of Mixed Methods in the Social & Behaviour Sciences* (Tashakkori & Teddlie, 2003) provides the first comprehensive review on the implementation strategies of mixed method approaches, while several other books that overview and discuss mixed method approaches have followed (e.g. Bryman, 2006; Creswell, 2008; 2009b; Neuman, 2011). There are also many journals that emphasise (e.g. *Journal of Mixed Method Research*), and promote the implementation of mixed method designs (e.g. *Qualitative Health Research*, and the *Journal of Social Research Methodology*) (Creswell, 2009a;2009b). The continuous changing, evolution and development of research methodologies, which implies the need for moving one step forward ‘within the research world’, may explain the rising popularity of mixed method designs within health and social care research. On the other hand, the complex and multiple research problems that social and health science researchers are called to investigate also explain the rising popularity of mixed method designs (Creswell, 2009a). Therefore, the implementation of a mixed method design, in this study, enabled the understanding of the complex and multidimensional nature of the concepts under examination. The latter was significant since this study not only aimed to examine the potential interrelationships between three complex phenomena, but also to explore older adults’ experiences.

As stated above the combination or not of quantitative and qualitative methods is a long-debated topic, however this approach is not new and uncommon in research. As the literature review of this study indicates, mixed method approaches are widely used within the self-stigma, loneliness and individualism/collectivism paradigms (see Chapters 2, 3, 4, and 5). For example, Livingston *et al.*, (2011) implemented a mixed method approach in order to examine and compare levels of self-stigma among people (age 18-65) with severe mental illness. By the implementation of a mixed method approach the author attempted to adequately address the study’s aim. Griffiths (2008) used a combination of quantitative and

qualitative techniques in order to investigate levels of self-stigma and ageism attitudes among out-patient older adults experiencing mental health problems (age range=65-92). Papadopoulos (2009) examined levels of public stigma towards mental illness and attempted to explain how this varies cross-culturally by utilising a mixed method approach, while under the same context Belshek (2010) examined how individual cultural values influence communication styles among Libyan students in the UK. Barg *et al.*, (2006) also used a mixed method approach to investigate levels of depression and loneliness, and their inter-relationships among African American and White older adults. By utilising a mixed-methods approach, the authors provide a nuanced picture of the phenomena. All the above studies used qualitative and quantitative methods in one single study in order to comprehensively examine a specific research problem. The quantitative phase of this study examined the prevalence, distribution and frequencies of both loneliness and self-stigma, and their conceptual inter-relationships with cultural values. The qualitative phase explored older adults' experiences of self-stigma and loneliness under the context of their cultural values. The utilisation of a mixed method design allowed the researcher to draw upon the strengths of each method and diminish their weaknesses (Conelly, 2009).

Mixed method designs also advance identification of eligible participants in research studies. That is, they allow the identification of research participants who have lived experiences of a phenomenon, and they are willing to share them. This proposition both has been highlighted by scholars within the mixed-methods literature (Thornton *et al.*, 2011; Moyah & Onwuegbuzie, 2013), and followed by many others. For example, Dean *et al.* (2011) examined back-pain among rural workers. The authors used a mixed method approach with the first stage to involve a questionnaire survey, and the second phase to involve a qualitative interpretative phenomenological analysis. The authors argued that the questionnaire survey advanced sampling identification for the second phase, while the findings of the first phase informed the interview guide of the second phase of their research. In this study therefore, a mixed method design was used in advancing sampling identification during the Phase 2 (qualitative approach).

Epistemology formulates and constructs researcher's views and perceptions about reality, truth and how research should be interpreted. Discussions and debates on whether distinct epistemological paradigms should be combined or not are well-documented in the literature (Migiro & Magangi, 2010; Sarantakos, 2013). The combination of quantitative and

qualitative methods in one single study advocates combining two distinct epistemological paradigms which may be considered as a key limitation of mixed method approaches. The two paradigms perceive reality, truth and research differently, and adopt different philosophical viewpoints (see section 6.3). Therefore their combination is rather problematic. Mixed method designs however go beyond the paradigm debates, and try to advance research by offering the combination of methods and approaches. That is, mixed method research is the tool of comprehending and explaining the structures and mechanisms of social phenomena, and the way these are influenced by one's subjective views (Sarantakos, 1998; Sarantakos, 2012). In this study a mixed-method design was utilised because it aligns with the researcher's epistemological stance (section 6.3), and allows the extensive exploration of self-stigma, loneliness and cultural values.

Although widely used and well-known within the social and health science research (Creswell, 2009a), mixed method approaches contain their own limitations. This method of inquiry is considered to be more time consuming and less cost effective. However, as stated above, this approach gives the researcher the opportunity to thoroughly investigate multidimensional concepts (Driscoll, 2007). Another problematic aspect of mixed method approaches refer to difficulties in implementing both quantitative and qualitative methods by a single researcher especially when these methods are performed simultaneously (Johnson & Onwuegbuzie, 2004; Cronholm & Hjalmarsson, 2011). However strategic planning can overcome this limitation. By using both methods a researcher can combine and build on the strengths of each method by avoiding their weaknesses (Connelly, 2009). They can also provide more insights and a better comprehension of the phenomenon under investigation that could be missed by the use of a single method (Johnson & Onwuegbuzie, 2004). Mixed method approaches require the researcher to be educated, familiar and knowledgeable of the techniques and methods of both quantitative and qualitative approaches, so that their mixing will be appropriately achieved. Once mixed methods are appropriately mixed they can ensure the findings' generalisation, and can provide robust evidence by converging and corroborating the study's results (Johnson & Onwuegbuzie, 2006).

To summarise, in this study an explanatory sequential mixed method design is used for five main reasons. First, the phenomena under examination are complex and multidimensional which constitutes their exploration often challenging. The implementation of a mixed method approach is considered to adequately meet this challenge. Second, a mixed method design

allows the researcher to maximise the strengths and diminish the weaknesses of each method by providing a nuanced picture of the concepts. Third, the utilisation of a mixed method design aims at identifying eligible participants and potentially maximise recruitment. Fourth, a mixed method design aligns with the epistemological underpinnings of this research study. Finally, mixed method designs are widely implemented in the loneliness, stigma and cultural literature.

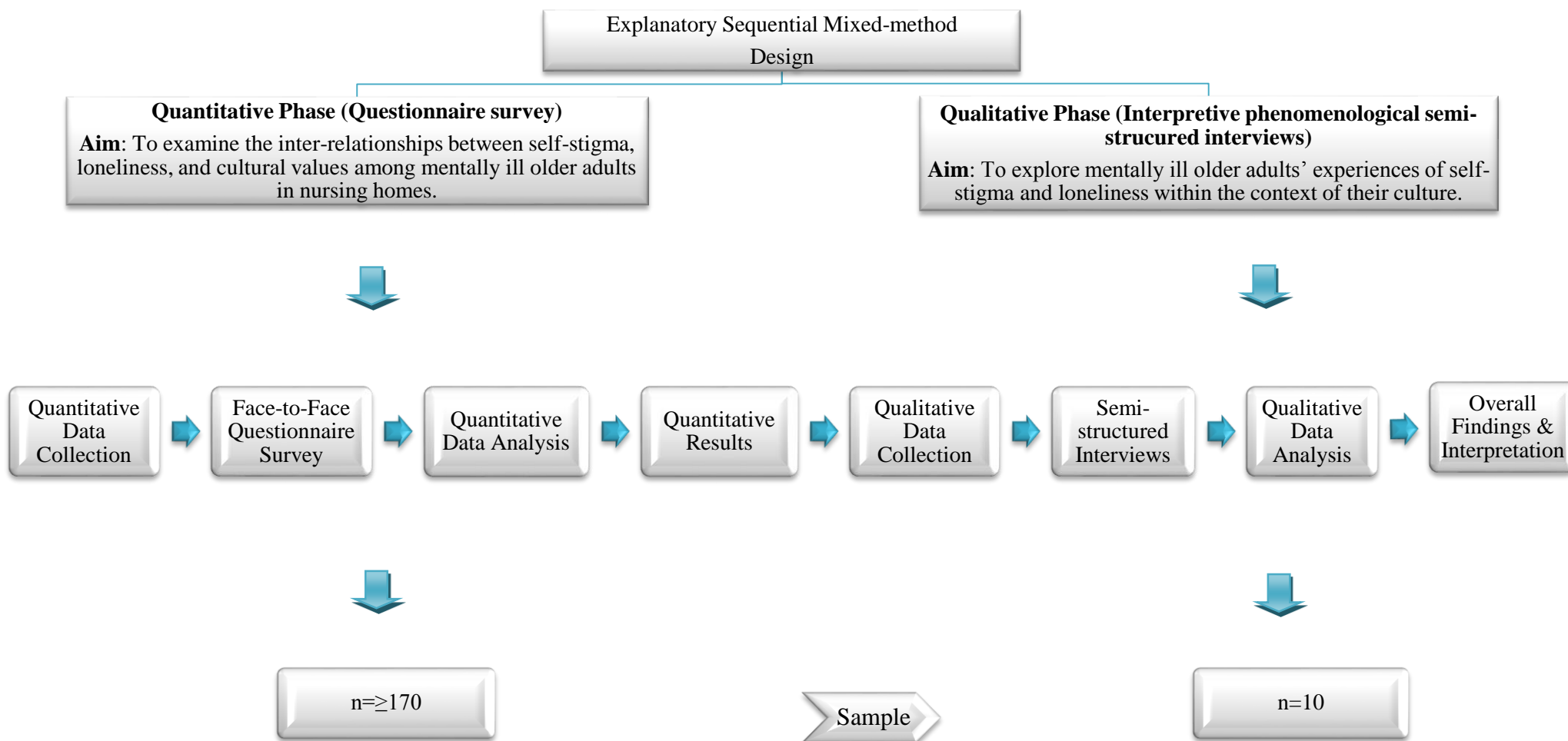


Figure 9: Utilised mixed methods design

6.3 Epistemology

Understanding the philosophical paradigms and defining one's epistemological stance are key activities researchers should engage with in order to comprehend the nature of knowledge, truth and reality. A researcher, through the decision of his/her epistemological stance, identifies his/her views about the world, the way knowledge should be obtained and shared, and the way truth should be investigated. Choosing an epistemological position allows researchers to realise their perceptions on the subjects of research interest, and how their perceptions should interpret research, methodology and methods. This section provides an exploration of the three philosophical paradigms, and justifies pragmatism as the epistemological underpinning of this research study.

The positivist paradigm is linked with quantitative methodology (Mack, 2010). Purists of positivism believe that reality is objective, independent of humans' conscience, and is governed by rigorous and immutable laws. That is, reality can be defined in the same way for all humans and independently of their consciousness because human beings share common meanings (Sarantakos, 2005). There is one objective, measurable reality which is shaped by the meanings that people attach to it. Positivists argue that absolute knowledge can be obtained through a descriptive and factual way as scientific propositions are discovered on data and facts (Scotland, 2012). Purists of positivism also believe that science is nomothetic, deductive, value free and is based on rigorous rules (Sarantakos, 2005). As a result, they view research as an instrument for studying social phenomena and their interconnections, and reality as objective and independent.

The interpretivist paradigm is linked with qualitative approaches, and opposes the propositions of positivist paradigm. One of their main differences concerns the conceptualisation of reality. Interpretivists argue that reality is not objective and measurable, but subjective (Sarantakos, 2005). According to the interpretivists there are numerous different realities that are personally experienced and constructed through humans' social interactions and interpretations. The purists of this school of thought argue that human beings have a dominant place in the social world, and that reality and social world is created through their subjective perceptions and interactions (Sarantakos, 2005; Gray, 2013). Interpretivists believe that social science is idiographic, inductive, not value free, and is not based to rigorous laws (Sarantakos, 2005). As a consequence, they view social research as the

instrument of understanding the meanings that people attach to their realities in order to identify and comprehend the sense of humans' lives.

Pragmatism, another type of epistemology, advocates the mixture of qualitative and quantitative approaches. There is a long standing debate whether or not researchers to combine and apply both methodologies in one single study (Sale *et al.*, 2002). Scholars over the past decades argued that quantitative and qualitative methodologies are two absolute different and incommensurable approaches, therefore, they cannot be combined and reconciled (Holden & Lynch, 2004). While positivists attach to reality an objective nature, and interpretivists give it a subjective one, pragmatists stand between these philosophical propositions by arguing that "although subjective meanings are relevant and important, objective relations cannot be denied" (Sarantakos, 1998, p.36). That is, there is an objective reality, but people have an input to it. Pragmatists believe that research should adopt a more pluralistic approach (Johnson & Onwuegbuzie, 2004) so as to enable the thorough understanding of research problems. Research therefore is the tool of explaining phenomena by understanding the structures and the mechanisms that govern them, and not to identify general rules (positivists) or humans' subjective experiences (interpretivists).

Pragmatism is the philosophical paradigm that informs this study. The paradigm aligns with my philosophy about the nature of social research, and the way social research should be implemented. It also enables the adoption of a mixed methods approach that I feel is necessary in achieving an in-depth exploration and understanding of the study research questions.

6.4 Summary

An explanatory sequential mixed methods design was utilised. A sequential mixed method design was considered to better address the complex nature of the concepts under investigation, advance our understanding, and provide a nuanced picture of them. A sequential mixed method design also allowed the identification of eligible participants through the questionnaire survey. Finally mixed method designs are widely implemented within the loneliness, stigma and cultural literature and align with the epistemological and philosophical underpinnings of this study.

Epistemology inter-relates and influence the way research is implemented. It is significant to know the various philosophical underpinnings so as to advance our understanding on how research, truth, reality and knowledge should be obtained and shared. Positivism, interpretivism and pragmatism paradigms view, understand and interpret reality, truth and research differently. All of these philosophical paradigms advocate useful propositions, yet pragmatism seems to align with my understating of reality, truth and science, and explains why it guided the methodology of this research study.

Chapter 7 Phase 1: Examining the inter-relationships between self-stigma, loneliness and cultural values

This chapter discusses the quantitative phase (phase 1) which examines the inter-relationships between self-stigma, loneliness and cultural subscriptions among older adults experiencing mental health problems in nursing homes. Based on the self-stigma, loneliness and cultural literature three hypothesis were formed. These are presented and discussed below. The chapter also discusses the methodology used. Specifically, it presents, explains, and justifies the utilisation of a face-to-face quantitative survey, eligibility criteria, the sampling technique, sample size, the screening and questionnaire tools used, analytical approach, and how ‘older adults’, ‘mental illness’, and ‘nursing homes’ have been defined in this study. A review on the history and current structure of long term care facilities in the UK is also presented. Finally, the chapter discusses the quantitative pilot study, the valuable lessons learnt and the resulting revised recruitment protocol used in the main study.

7.1 Phase 1: Questionnaire survey

7.1.1 Aim and objectives

The aim of the first phase of this study was to examine the inter-relationships between self-stigma, loneliness, and cultural values among older adults with mental health problems residing in nursing homes.

This was achieved through the following set of objectives:

- To assess the prevalence of self-stigma and loneliness among mentally ill older adults in nursing homes, including whether and how prevalence varies within the individual level of cultural values.
- To examine whether and how socio-demographic background factors help to explain self-stigma and loneliness prevalence.
- To examine whether and how the individualism-collectivism paradigm helps to explain within-cultural self-stigma and loneliness.
- To examine the conceptual relationship between self-stigma and loneliness.

7.1.2 Hypotheses

The literature review of this study revealed that alienation and social withdrawal are two of the most common reported components of self-stigma among people experiencing mental health problems (Mosanya *et al.*, 2014; Boyd *et al.*, 2014) (see chapter 2). People with mental health problems therefore are reluctant to interact with others and/or to form intimacy and/or social relationships with them because of the negative attitudes that internalise towards themselves. An inadequate social environment which minimises opportunities for social integration, along with the lack of close relationships which reduces chances for emotional integration, results to feelings of loneliness (Weiss, 1973) (see chapter 3). Mental illness self-stigma (through its main components: social withdrawal and alienation) minimises opportunities for social and emotional integration, and may therefore influence feelings of loneliness. I therefore hypothesised that there is an inter-relationship between self-stigma and loneliness.

The literature also revealed that the individualism/collectivism (I/C) paradigm is the most widely used cultural dimensions in categorising social patterns and types of interpersonal relationships (Kim, 2009) within and across cultures. I/C has also been widely used in explaining psychosocial phenomena and identifying variations on individuals' attitudes, behaviours and values (Okoro *et al.*, 2008). According to the literature individualism refers to independency and autonomy, where collectivism refers to interdependency, interconnectedness and family harmony (Triandis, 1989; Scott *et al.*, 2004; Papadopoulos *et al.*, 2013) (see chapter 4). Triandis (1996; 1998) proposes that cultures are not absolute collectivistic or individualistic ones. That is, individualism is dominant and emphasised in some cultures, while collectivism is prioritised in others. In relation to within cultural variations, Abdullah and Brown (2011) suggest that some individuals are deeply interconnected with their cultural backgrounds. However, they argue, others may not subscribe to the same ethnic primary values. People who belong to same cultural backgrounds may not therefore identify and/or associate themselves with the norms, beliefs and patterns of the dominant culture. These cultural differentiations may therefore influence the way people experience phenomena. The horizontal/vertical individualism collectivism (VHIC) cultural model by Triandis and colleagues (1998; 2001), which is influential to this study, explains these within-cultural variations in relation to loneliness and self-stigma among mentally ill older adults in nursing homes.

More specifically, in relation to mental illness stigma the literature (chapter 5) suggests that public stigma is prevalent in traditionally collectivistic societies. For example, Tzouvara and Papadopoulos (2014) identified that levels of mental illness public stigma is moderate/high among people belonging to traditionally collectivistic cultures (Greek). In addition, people subscribing to collectivistic-oriented cultural backgrounds are more likely to stigmatise mental illness compared to their individualistic-oriented counterparts. For example, Papadopoulos *et al.*, (2013) conducted a cross-sectional UK-based study that examined cross-cultural variations on public stigma. The findings indicated that collectivistic-oriented participants (Chinese and Greek samples) held more stigmatising attitudes towards mental illness than their individualistic-oriented counterparts (American/white-British).

Empirical findings on self-stigma reveal similar trends (chapter 5). For example, Brohan *et al.*, (2010) found higher levels of self-stigma among people experiencing mental illness in collectivistic countries (Greece) compared to individualistic ones (Lithuania). Conner *et al.*, (2010) found that African Americans older adults internalise significantly higher levels of stigma compared to their White American counterparts, while in a more recent study Chen *et al.*, (2015) found high levels of stigma among Chinese Americans immigrants who were seeking mental health care. Therefore, there are clear indications that mental illness stigma is more likely to occur within collectivistic-oriented cultural contexts. People that value collectivism are prompt to retain their intimacy relationships with their family and their in-groups, to follow, respect and concur with the norms, patterns and behaviours of their in-groups, and to maintain harmony and interconnectedness with their in-groups (chapter 4). Indications which may cause disruptions on the above notions may be considered as an 'abnormal' situation and may perceive devaluating behaviour. This may cause discriminatory and stigmatising attitudes to worsen. Mental illness and therefore people experiencing mental health problems are more likely to be stigmatised, and to be linked with perceptions of dangerousness and aggressiveness. People with mental illnesses who value collectivistic cultural values may internalise all the negative perceptions towards them, and therefore may become self-stigmatised. Based on the literature review and the theoretical underpinnings of this study, I hypothesised that older adults experiencing mental health problems in nursing homes and subscribing to collectivistic cultural dimensions are more likely to become self-stigmatised compared to their individualistic-oriented counterparts.

The literature review of this study also indicates variations on loneliness across and within cultures. For example, Fokkema *et al.*, (2012) found that older adults living in Southern and

Central European countries are more likely to feel lonely than their Northern and Western counterparts. Panagiotopoulos *et al.*, (2013) compared widowhood and well-being among British-born (n=60) and Greek-born (n=61) Australian migrant older adults and found that Greek-born older adults report higher loneliness, increased symptoms of depression, and worse self-rated health compared to British-born older adults. Lykes and Kemmelmeier's (2014) revealed that prevalence of loneliness is higher among participants living in collectivistic oriented cultures compared to individualistic oriented ones. In a recent study de Jong Gierveld *et al.*, (2015) found that older adult immigrants from Europe, but French and British origins, report higher loneliness compared to Canadian born older adults, while older adult immigrants from non-European origins, report, overall, the highest levels of loneliness, and score significantly higher to loneliness compared to those born in Canada. Empirical evidence therefore indicates that older adults who subscribe to traditionally collectivistic cultural orientations are more likely to experience loneliness. Collectivistic older adults may have greater expectations from their relationships, and thus, may meet greater disappointment when these expectations are not met (Dykstra, 2009), which may result in loneliness. In addition, collectivistic-oriented older adults foster family interconnectedness and harmony. Life changes that results and/or cause disruptions to family interconnectedness and harmony may therefore influence experiences of loneliness among this population. For example, relocation into nursing homes may cause disruptions to family interconnectedness, and therefore, may influence loneliness among collectivistic-oriented older adults in nursing homes. Based on the literature and the theoretical underpinnings of this study, I hypothesised that older adults experiencing mental health problems in nursing homes are more likely to experience loneliness compared to their individualistic-oriented counterparts.

The hypotheses of this study were:

Hypothesis 1

There is an inter-relationship between self-stigma and loneliness among mentally ill older adults residing in nursing homes.

Hypothesis 2

Older adults with mental health problems residing in nursing homes and valuing collectivism are more likely to experience self-stigma and loneliness.

Hypothesis 3

Older adults with mental health problems residing in nursing homes and valuing individualism are less likely to experience self-stigma and loneliness.

7.2 Quantitative method

Quantitative methods make use and focus on objective instruments and statistical analyses of data, and emphasise generalisation of findings. They also aim to identify the associations, relationships, and causality between independent and dependent variables among a specific population (Babbie, 2010; USC Libraries, 2013). The use of particular quantitative methods during a research study depends on the study's aims, objectives and research questions. This study examined the relationships between self-stigma, loneliness and cultural values among older adults experiencing mental illnesses in nursing homes for which a face-to-face paper based questionnaire survey method was employed.

Face-to-face surveys adopt a standardised number of questions which is followed until the end of the interview. The researcher travels to a particular location and meets personally the participant in order to conduct the interview. Face-to-face surveys are particularly appropriate when examining populations that may lack writing and reading skills and may have difficulty in responding to the questions due to physical disabilities (Doyle, 2005). These reasons help justify the utilisation of a face-to-face survey in the current study since participants are of old age, and may suffer from mental and physical disabilities. Thus, a face-to-face method gives the researcher the opportunity to examine this population at their convenience and location. In addition, the researcher may be able to establish relationships of trust with the respondents (Oatey, 1999). This was important because, in this study, a follow-up semi-structured method was also applied (phase 2). By establishing a relationship of trust, participants might be more willing to share their thoughts and perceptions about loneliness and mental illness self-stigma. Therefore, the opportunity of building a relationship of trust between the researcher and the participants was highly beneficial.

Face-to-face surveys also ensure higher response rates and therefore lower missing data rates since researchers are able to obtain a greater control of the data collection process, and the participants' environment in comparison with other types of surveys such as telephone surveys and e-mail surveys (Doyle, 2005). For example, in a face-to-face survey the researcher can be more confident that the participants will respond to all the questions, while

their attention will not be disrupted when filling out the questionnaire by other external factors.

Face-to-face questionnaire surveys come with their own limitations. The cost and expenditures which are associated with the implementation of a face-to-face survey are two of its main limitations. The interviewers have to travel from the one geographical area to the other. However, in this study all interviews were conducted in one geographical area (origin of Bedfordshire) so as to reduce travel related costs. The greater cost of face-to-face surveys is ‘interviewed bias’ (Doyle, 2005). The researcher should ensure that the respondents are not influenced by verbal or non-verbal cues. In this study, to reduce interview bias to be reduced the researcher read the questions as they appear in the questionnaire without paraphrasing them or changing the questions order or trying to emphasise certain questions with her voice.

Overall, face-to-face questionnaire surveys were viewed to be an advantageous option since they enabled the researcher to reduce the likelihood of missing data and increased response rates. This in turn increases the likelihood of sample representativeness and generalisability. Although this method may introduce interviewed bias and may be thought as costly, it is an ideal method for this study’s population. That is, older adults who may suffer from both mental and physical disabilities and may have poor writing and reading skills.

7.2.1 Eligibility criteria of participants

In this study, participants were selected according to the below inclusion and exclusion criteria:

Inclusion Criteria

- Older adults ≥ 60 years old.
- Older adults suffering from mental illness.
- Older adults who possess the cognitive ability to participate in the study.
- Older adults residing in nursing homes located in the county of Bedfordshire.
- Older adults who speak and understand the English language.

Exclusion Criteria

- Older adults < 60 years old.
- Community dwelling older adults.

- Older adults without mental health problems.
- Older adults who do not possess the cognitive abilities to participate (such as end stage Alzheimer or other degenerative disorders psychosis, or severe forms of aphasia) (section 7.2.4.1).
- Older adults who do not understand or speak the English language

In this study speaking and understanding the English language was a key eligibility criterion. This criterion was applied because of practical issues, namely the financial and time related costs involved in translating (and back translating) the questionnaire tool into all of the potential languages in England. The researcher, therefore, decided to concentrate on the participants who could speak and understand English. The aim of this study was to explore cultural differences at the individual level and not at the cultural level which also explains why non-English speakers were excluded. Finally, according to ONS (2011) almost 95% of the population in East England reported English as their main language. However, excluding older adults who did not speak and understand the English language is likely to have introduced sampling bias. For example, non-English speakers might differ in the way they understand and interpret loneliness and self-stigma, and they might therefore experience self-stigma and loneliness differently to English speaking older adults. By excluding them we therefore introduced sampling bias since we focused purely upon older adults who were able to understand and speak the English language. Including different languages would have also allowed the cross-cultural (and not only within-cultural) examination of the concepts. However, as discussed earlier practical reasons informed the researcher's decision to exclude older adults who could not speak and understand English. It is worth mentioning that the results of the quantitative study further justify and explain this criterion (excluding older adults who do not speak and understand English). As can be seen in Chapter 8, Table 8 the 99.3% of older adults' assessed stated English as their first language. Therefore, the majority of the sample of this study was English older adults who understood and spoke the English language.

7.2.2 Defining 'older adults'

One challenge of this study was to define 'older adults', and thus, determine this study's target population. "The ageing process is of course a biological reality which has its own

dynamic, largely beyond human control. However, it is also subject to the constructions by which each society makes sense of old age...The age of 60 or 65, roughly equivalent to retirement ages in most developed countries, is said to be the beginning of old age ... Other socially constructed meanings of age are more significant such as the roles assigned to older people; in some cases it is the loss of roles accompanying physical decline which is significant in defining old age” (John & Kumar, 2013, p. 168).

Gorman (1999) argues that not only chronological indicators should be considered when defining older adults, but also social aspects of age. That is, how aging process is constructed and influenced by social perceptions and norms within different cultural contexts. Old age is interchangeably linked with retirement processes which are often higher for men than women, and vary from country to country. Public Health England (2013a) argues that the definition of old and/or older adults is not universally agreed. Also individuals seem to have different views on what they perceive to be old or not. Age is not an accurate indicator of mental or physical frailty, yet increasing age associates with higher probabilities of suffering a wide range of health problems, while it limits functional capacity (Public Health England, 2013a). In England, the Friendly Societies Act define old adults as every person which is above the age of 50 years, however the pension schemes only include older adults from 60 or 65 years old and above (WHO, 2013). The inconsistency on defining ‘older adults’ is also apparent within the United Nations since there is no a standard criterion that has been adopted when defining old age (WHO, 2013). They, however, use 60+ years old as a cut-off point to indicate the older population.

The literature, within and outside the UK context, presents the same inconsistency when examining older adults. Some studies adopt the numerical criterion of 60 years old (e.g. Conner *et al.*, 2010; Jahn *et al.*, 2011; Lim & Kua, 2011), while others adopt the numerical criterion of 65 years old (e.g. Drageset, 2004; Victor *et al.*, 2005; Drennan *et al.*, 2008; Golden *et al.*, 2009). It could, therefore, be argued that adopting a numerical criterion that determines ‘older adults’ in research studies is left upon the researchers’ judgement. The inconsistency on the definition of old age, along with, the lack of a universally agreed numerically criterion of old age (Caldwell *et al.*, 2008) resulted to the utilisation of ≥ 60 years old, as the cut-off age that defines ‘older adults’, and thus determines the target population of this study.

7.2.3 Care in the UK: setting the scene

Long-term care facilities have a long history in the UK. For example, some early hospitals (e.g. London's St Bartholomew's [1123] and St Thomas's [1200]) began as providing nursing shelters to the ill, with many of them to belong to the older age groups (Lievesley *et al.*, 2011). In the industrial era the establishment of the New Poor Law (1834) led to the creation of workhouses which acted as shelters for those who were unable to support themselves. Historically, this is the first (integrated) attempt of the state to develop a "social welfare system" (Lievesley *et al.*, 2011). By the 1850s the majority of the people forced to live in the workhouses were the old, orphaned, unmarried women, infirm, the physically and mentally ill. Growing complaints about the efficient function of the workhouses resulted to the Metropolitan Poor Act, which re-established workhouses' role. In 1930, officially, the workhouse era ended, however some of the buildings were still used to accommodate the old and sick (Higginbotham, 2015).

In the 1980s, a large number of care homes were owned and run by the local authorities. The funding reforms in the 1990s resulted to the decline of the number of homes owned by the local authorities, and the private sector to grow significantly in size (Garg *et al.*, 2009). The large decline of NHS hospital beds, to overall all categories of the population (figure 10), also resulted in an increase of the proportion of privately owned care homes (Lievesley *et al.*, 2011; Donnelly, 2014). A recent study by the Organisation for Economic Co-operation and Development substantiates this by revealing that the UK has the lowest number of NHS beds per capita (2.95 beds per 1000 people) compared to 23 European Countries (Donnelly, 2014). The National Minimum Wage and the National Minimum Standards for care homes also exacerbated the situation. Local authorities were under financial pressure, and could not maintain low fees. Small size homes with low occupancy (that were usually run by public organisations) were forced to close. Also homes without lift, en-suite facilities, and high number of shared bedrooms were more likely to close because of the high costs of meeting the new minimum standards (Lievesley *et al.*, 2011).

In England there is a mixed long-term care economy, with the majority of the care to be provided by the private sector (NIHR School for Social Care Research, 2011). The financial pressures, with low fee contracts and high supply costs, lead to large corporate enterprises to nearly monopolise the long-term care provision. Large corporate enterprises are also more likely to meet regulatory recruitments and sustain economies of scale resulting in the increase

of the average size of care home beds to almost over 30 beds (Gerg *et al.*, 2009). The amount and the size of care homes has significantly risen, yet future estimations suggest that by the year 2034 more than the double amount of existing care homes will be required (Macdonald & Cooper, 2007) to meet the needs of the rapidly growing aged population, in the UK.

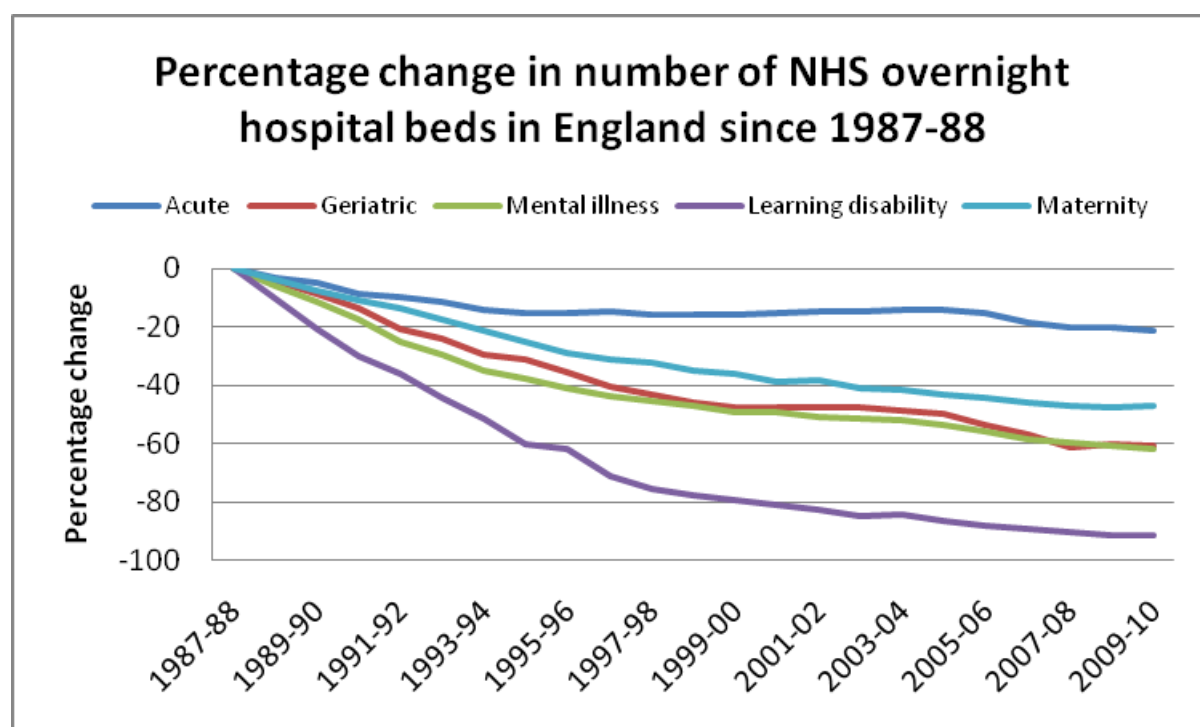


Figure 10: Percentage decline of NHS hospital beds (seen in Lievesley *et al.*, 2011)

In England, current estimations suggest that there are 13,134 residential care homes with a total capacity of 247,824 people, and 4,672 nursing homes with a total capacity of 215,463 people (Davies *et al.*, 2014); while there are approximately 431,500 older adults and people with disabilities residing in long-term care facilities (AgeUK, 2015a), in the UK. The increase number of the older population signifies an increase in the number of older adults who might reside in long-term care facilities. It is worth mentioning that the number of older adults currently amount to 14.5 million people (AgeUK, 2015a)

Care homes provide a wide range of services. Many factors are key determinants on the types of services provided by homes. That is, the size of the home, its location, its specialisation (for example, whether or not it provides care for dementia, and/or learning disabilities), its facilities, and its culture. Also a key distinction is whether they provide constant nursing

tasks, or not (Forder & Netten, 2000; Darton *et al.*, 2003). Homes that provide full nursing care (qualified nurse on duty 24 hours a day), and can support people with physical and/or mental disabilities are referred to as nursing homes, while homes that do not provide full nursing care (residents are relatively healthy, but without constant nursing needs) are referred to as residential homes (CarersUK, 2014). The main difference between the two is the level of independency of their residents. The legislation (Care Standards Act came into effect in 2002) abolished the distinction between residential and nursing care homes, and established a series of National Minimum Standards that care providers must meet (Gerg *et al.*, 2009), the terms (residential and nursing care homes) are used until today. Annual inspections by the Quality Care Commission (former Commission for Social Care Inspection or CSCI) on 38 standards in 7 different topic areas oversees the quality of care provided, and reassures that care home providers comply with the state's regulations (Gerg *et al.*, 2009; NIHR School for Social Care Research, 2011). Despite the state's efforts to provide and maintain high quality of care home services, care homes are often under media scrutiny for care home staffs' abusing behaviour towards residents (e.g. Holt & Lee, 2014; BBC News, 2014; Dugan, 2014).

As stated earlier the number of older adults causing inevitable changes not only to UK society as a whole, but also to the characteristics of care home populations. According to the ONS (2014) the care homes population is ageing, with 59.2% of residents aged 85 years old and over. Female residents outnumber males, since there are 2.8 females for each male aged 65 years and above (ONS, 2014). Residents of care homes therefore tend to be older, female, and with greater and more complex healthcare needs (British Geriatric Society, 2011). This signifies that care homes residents may remain dependent on others for long periods of time, and usually have poor life prognosis (Caldwell & Moiden, 2000). The increased needs of the ageing population in care homes in relation to the decline of long-term hospital beds raises questions as to what extent nursing and residential care homes can cope, meet and potentially adequately satisfy the health and social demands of this age group.

For the purposes of this study, and by considering the current structure of care homes in England, nursing homes were defined as homes where constant nursing is provided (EAC, 2013). More specifically "a home registered for nursing that provides personal care (help with washing, dressing and giving medication), and also has a qualified nurse on duty twenty-four hours a day to carry out nursing tasks. These homes are for people who are physically or

mentally frail or people who need regular attention from a nurse” (EAC, 2013). The eligibility criteria of the nursing homes were:

- Provide nursing care to older adults.
- Provide basic and/or specific mental health services to older adults.
- Are located in Bedfordshire.

The focus of this study was on nursing homes rather than all type of care homes. The number of older adults with mental health problems residing in nursing homes increases (AgeUK 2015a). According to the Health and Social Care Information Centre (2013) around 30000 older adults suffer from a dementia or a type of mental illness in nursing homes in England. Despite this, there are a limited number of studies aimed at exploring the mental health and wellbeing of this particular population (older adults with mental health problems residing in nursing homes) which is problematic given their complex health care needs and the increasing size of this population. This study therefore focused on nursing homes in an attempt to boost the evidence in this area through identifying how this population views and understands their mental illness, and how these perceptions interrelate with loneliness. Practical issues including limited resources (e.g. time and money) meant that the focus of this study could not feasibly be broader than a single type of population.

7.2.4 Defining mental illness

When the term ‘mental illness’ is used in a research project clarification of its meaning is essential. Leighton (2008) in a small study identified conceptual misconceptions among participants and the literature about the meaning of the term ‘mental illness’. The term is often used interchangeably to the term mental health. The two concepts are related, yet they differ and should be provided separately (cited in Leighton & Dogra, 2009). According to WHO (2014) mental health “is defined as a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community”. However, the above definition has been criticised because it lacks essential components that may affect and influence the individuals’ psychological state, that is, the individuals’ social and physical environment (Leighton & Dogra, 2009).

On the other hand mental illness is defined “as all diagnosable mental disorders” or “health conditions that are characterized by alterations in thinking, mood, or behaviour (or some combination thereof) associated with distress and/or impaired functioning” (Centres of Disease Control and Prevention, 2011). This definition of mental illness coexists, and is similar to the definition of mental illness that has been provided by the National Health Service (NHS Inform, 2013). The latter definition was adopted for the purposes of this study. The definition aligned both with the context of the study and the interRAI-LTCF screening tool that was used in assessing older adults’ psychological and cognitive well-being. Information about the screening tool and assessments procedures follow.

7.2.4.1 Identifying mentally ill older adults: the interRai-LTCF screening tool

The InterRai team was established in 1992, and is a non-for-profit research consortium (<http://www.interrai.org/>) with a wide range of professionals from different countries. It is consisted of 50 clinicians, researchers and health administrators from 25 countries (including the UK) sharing the same vision. That is, the collection of adequate clinical information across different countries, and within different service contexts. This will enhance the frail individuals’ well-being, and will positively impact on the efficient distribution of resources (Gray *et al.*, 2009).

The interRai consortium has developed a number of assessment tools which have been used in various clinical, and non-clinical settings (Hirdes *et al.*, 2002; Hirdes *et al.*, 2008; Onder *et al.*, 2012; Wellens, 2012). In this study, the interRai-LTCF assessment tool was utilised in assessing the cognitive and psychological well-being of older adults in nursing homes. The initial interRAI-LTCF- known as Minimum Data Set- was used as an assessment tool of determining care needs, developing criteria of patients’ eligibility, providing significant information regarding nursing home residents, supporting the monitoring procedures of services efficiency, constructing measurements’ quality, and finally contributing to a better resource distribution. The new up-dated version of the interRai-LTCF instrument consists of and builds upon a common set of screening items. This common set of items is based on identical definitions, observation frameworks, and response coding. The instrument is therefore ideal in assessing, and comparing characteristics of older adults among different settings (Gray *et al.*, 2009).

The interRai-LTCF is a reliable (Carpenter, 2006; Gray *et al.*, 2009) and validated screening tool (Carpenter, 2006; Hiders *et al.*, 2008) which has been widely used in the nursing home literature (appendix 1). The screening tool consists of three separate sections: a) *cognition*, b) *communication, vision and hearing*, c) *mood and behaviour*. In this study, four outcome measures were utilised: a) *the Cognitive Performance Scale* (CPS), which assesses participants' cognitive ability b) *the Depression Rating Scale* (DRS) & *Anhedonia Scale* (AHS), which assess participants' depression, anxiety and mood disorders, and c) *the Aggressive Behaviour Scale* (ABS) that assesses participants' aggression mood. Research reveals that aggressive behaviour is strongly associated with mental ill health (Tsiouris *et al.*, 2011). The ABS was therefore utilised as proxy in identifying mental illness. The interRAI-LTCF tool also involved self-reported mood items. The self-reported items can be completed by the assessors when residents have no cognitive ability to do so.

The assessment is based on various sources of information, and is designed to be used by clinical professionals such as nurses, family physicians, social workers, and other health professionals (interRai, 2013). Communication with the residents and the staff members, observations, and review of the clinical records are recommended. Where communication with residents is not feasible due to communication or cognitive impairment and/or where conflicting information exists, then the assessment is based on the assessors' good judgment (Hidres *et al.*, 2008; Gray *et al.*, 2009; Onder *et al.*, 2012). The scales summarising main domains are computed after the assessment is ended.

As stated above the interRai screening tool has been designed to be used by clinical professionals. Therefore, in this study the assessments were completed by the staff members of the nursing homes (nurses and carers) based on their communication with older adults, their observations, and the review of older adults' clinical records. Where communication was difficult, the assessment was performed based only on staff members' observations, good judgment, and review of the clinical files. The tool was mainly completed by the nurses on behalf of the residents.

7.2.5 Sampling technique

A two stage randomised sampling technique was used. The first stage involved a randomised cluster sampling technique. Cluster sampling technique refers to the procedure where researchers “*choose the study units progressively*” so that the clusters will be initially identified, and then participants are sampled from smaller groups within the clusters

(Sarantakos, 2013, p.174; Bryman, 2012). This technique requires sampling frames. A comprehensive frame of all eligible Bedfordshire-based older adult nursing homes was used in identifying this study's clusters (nursing homes). The nursing homes comprehensive frame has been developed by the Institute of Diabetes for Older People, in the University of Bedfordshire. The 'nursing homes list' provides detailed information about the nursing homes located in Bedfordshire and Hertfordshire. The information provided involved the name of nursing homes, address, phone number, type of ownership (individuals/organisations), specialism by age (younger adults/older adults), type of services provided (e.g. mental illness), and local authority (Bedford, Luton, Central Bedfordshire and Hertfordshire). The nursing homes in Hertfordshire are also included in the 'nursing home list'; however, they were not sampled due to this study's time and cost restrictions.

The second stage involved a simple randomised technique in sampling participants from the sampled clusters until enough participants have been recruited, as per the study sample calculation. Randomised sampling techniques do enable claims of representativeness, and thus provide opportunities for generalisations of the findings to the target population. This justifies the utilisation of a randomised sampling technique. Randomised sampling techniques are, however, more time consuming and less cost effective compare to non-randomised sampling techniques (Sarantakos, 2013). They also require a sample size calculation so that the sample size to be determined. For this study's purposes a sample size calculation was conducted, and below discussed.

7.2.5.1 Sample size

According to the Health and Social Care Information Centre (2013) around 30000 older adults with mental health problems were living in UK-based nursing homes. Therefore, the number of the target population was set at 30000, with a confidence level set at 95%, and confidence interval set at 7.5. Confidence intervals "are a standard way of expressing the statistical accuracy of a survey-based estimate" (Yang & Bolton, 2009, p. 2). The wider the level of confidence interval, the higher the estimated error and the less confident one should be that the survey results report values close to true figures (Yang & Bolton, 2009). According to the sample size calculation, the sample size for this study was determined to ≥ 170 older adults.

A 7.5 confidence interval was set because of practical issues. A smaller confidence interval would have required a larger sample size. This would have further increased the risk of not being able to achieve statistical power. Therefore the researcher decided to set a wider confidence interval but also acknowledging the higher estimated error this created and its impact on external validity. The confidence level of this study was set at 95% because the researcher wished to maintain high confidence that the survey results reported values close to true figures (Yang & Bolton, 2009).

The Creative Research Systems survey software was used for conducting the sample size calculation

7.2.6 The questionnaire tool

The first section of the questionnaire tool consisted of socio-demographic questions so that any potential correlations between these variables and levels of self-stigma, loneliness and cultural values were able to be identified. Socio-demographic characteristics have been previously identified to associate with levels of loneliness (e.g. Victor & Bowling, 2012), and self-stigma (Brohan *et al.*, 2010). The second section contained the reliable short form of the ‘General Health Questionnaire’ (GHQ-12) which measures individual’s mental wellbeing (Goldberg *et al.*, 1997) by focusing on the inability of carrying out every day functions, and the experience of distressing events. The brief GHQ-12 has been widely used to assess mental health well-being among older adults, and has showed good internal consistency (Bowling, 2007; Zulkefly & Baharudin 2012), and test-retest reliability (Hankins, 2008). The tool has been used in clinical and non-clinical settings, including for older adults (Paul *et al.*, 2006; Hu *et al.*, 2007). The GHQ-12 was used as a means of verification of the results of the mental health screening tool (section 7.3.4.1), since it provided key subjective information on participants’ mental health well-being.

The validated and reliable short form of the ‘Internalised Stigma of Mental Illness’ (ISMI) scale was used in measuring levels of self-stigma. The scale consists of 29 items with 4 Likert-scale response options (1= strongly disagree and 4= strongly agree). The ISMI scale: a) has showed high internal consistency ($\alpha=0.90$), test-retest reliability ($r=0.92$), and construct validity (Ritsher *et al.*, 2003; Brohan *et al.*, 2010; Ehrlich-Ben Or *et al.*, 2013), b) has been widely used on assessing mental illness self-stigma (Livingston & Boyd, 2010) and c) has been utilised among older adults (Werner *et al.*, 2009). The ISMI scale consists of five

subscales: alienation, stereotype endorsement, social withdrawal, stigma resistance, and discrimination experience. The alienation subscale examines individuals' subjective experiences of being less valuable members of the society. The stereotype endorsement subscale measures the degree of individuals' endorsement of stereotypes about mental illness. The social withdraw subscale examines individuals' feelings about social perceptions regarding mental illness. The stigma resistance subscale assesses the consequences of mental illness on individuals' lives. Finally, the discrimination experience subscale measures individuals' perceptions of discriminate attitudes against them due to their mental illness. Initially the Self-Stigma Mental Illness Scale (SSMIS) was considered to be the most adequate scale on measuring self-stigma because it has been developed based on the self-stigma model by Corrigan *et al.* (2006) (chapter 2). However, the SSMIS scale is a 40-items long scale, and thus requires quite a lot assessment time. The scale has also been criticised because it uses quite sensitive terms that could offend people experiencing mental health problems (Corrigan *et al.*, 2006; Corrigan *et al.*, 2012), and therefore to influence their psychological well-being. The short form of the SSMIS scale was then considered as more appropriate tool on assessing self-stigma levels. It is, however, a relatively new instrument (Corrigan *et al.*, 2012), and has not previously been implemented among older adults.

Loneliness was assessed by a single self-reporting question. Older adults are asked to report how lonely perceive themselves to be on a scale from always lonely, often lonely, sometimes lonely to never lonely (Victor & Bowling, 2012). The one self-reported question on assessing loneliness among older adults has become a customary within the UK studies (e.g. Victor *et al.*, 2005; Victor & Yang, 2012; Victor & Bowling, 2012). Also, self-reporting measures are simple and ideal among older adults, while assessing participants' directly feelings of loneliness (Victor & Yang, 2012). In this study, loneliness is defined as a multi-faceted subjective phenomenon. The utilisation of one self-reported measure of loneliness may be thought to undermine this study's definition, and thus fail to examine loneliness multidimensional nature. The qualitative arm of this study, however, aims at overcoming this quantitative limitation.

Finally, the short version of 'Vertical-Horizontal Individualism-Collectivism' (HVIC) (Sivadas *et al.*, 2008) scale was used. The scale consists of 14-items on a nine Likert-point scale from strongly disagree to strongly agree, and measures individual levels of individualistic, and collectivistic cultural values. The scale also measures vertical and horizontal cultural subscriptions. The tool has shown good reliability, and has been assessed

in four countries (US, China, Denmark, and India) (Sivadas *et al.*, 2008). Sivadas *et al.*, (2008) argue that the coefficient alpha of the 14-item scale was higher in comparison to Triandis and Gelfand's (1998) 16-item scale, and Singelis *et al.*'s (1995) 32-item scale.

The participants of this study are of old age, thus they sometimes might be unable to read the questions by themselves, and/or to hold a pen to fill out the questionnaire, and/or sometimes feel too fatigued to do so. In overcoming these difficulties the researcher read the questions to the participants, and ticked the participants' answer on the questionnaire. In addition a "large-type version" of the questionnaire was administrated to the participants so they would be able, if they wished to, to follow the questions that the researcher asked (Drageset *et al.*, 2011, p. 613).

7.2.7 The quantitative pilot study

Baker (1994) states that "a pilot study is often used to pre-test or try out a research instrument (pp. 182-183)". Secomb and Smith (2011) give weight to the latter argument by stating that pilot studies provide researchers the opportunity to not only pre-examine the methods of a research design, but also to pre-examine the data collection instruments, and recruitment procedures. This provides useful information to the researchers about the feasibility of a research project, while giving the researchers the opportunity to overcome any difficulties, re-think and possibly re-design potential faulty procedures. Conducting a pilot study is therefore important. Both phases of this study have been pilot tested. In this section the objectives of the quantitative pilot study, and the lessons learnt from it are discussed, while a detailed discussion of the qualitative pilot study can be viewed in chapter 9, section 9.5.2.

7.2.7.1 Objectives of the pilot study

As stated earlier pilot studies offer valuable information in relation to the feasibility of a research project. Study designs, recruitment procedures, sampling methods, and response rates are some among a number of important factors that are examined during a pilot study. Prior knowledge give opportunities (where and if it is necessary) for re-addressing these important aspects of research, and therefore implement a rigorous study. The objectives of the quantitative pilot study concerned:

- a) The recruitment procedures of both nursing homes, and older adults.
- b) The response rates of both nursing homes, and older adults.

- c) The administrative procedures of the screening tool, and the questionnaire.
- d) The organisation and presentation matters of the questionnaire tool.
- e) Problems with understanding certain questions.
- f) The sensitivity of the questions included in the questionnaire.
- g) The duration of the assessments, and the questionnaire survey.
- h) The effectiveness of the screening tool.

7.2.7.2 Sampling technique and sampling size of the pilot study

The pilot study did not make claims for neither sample representativeness, nor for data generalisation, instead its implementation served technical purposes (section 7.6.1). Therefore, a non-randomised sampling technique was utilised, specifically a quota non-randomised sampling technique. Socio-economic deprivation details and the mortality rankings of Bedfordshire origin (Public Health England, 2011) were used as ‘quotas’. Deprivation details and mortality ranking were used as quotas due to the wide differences presented between Luton and Central Bedfordshire. More specifically, Luton belongs to a low socioeconomic decile (4), is more deprived, and is among the worst national local authorities (108th out of 150 local authorities) according to the mortality rankings in the years 2009-2011. While Central Bedfordshire is the least deprived (socioeconomic decile 10), and is among the best national local authorities (33rd out of 150 local authorities) according to the mortality rankings in the years 2009-2011 (Public Health England, 2013b). Seven nursing homes were approached to participate in the pilot study. Participants were then purposively selected according to this study’s eligibility criteria (section 7.3.2).

One nursing home and six older adults participated in the pilot study. Participants were assured that the study was voluntary. Prior to the implementation of the pilot study participants were given an information sheet, and a consent form in increasing anonymity and data confidentiality. For an overview of the tool, participant information sheet, and informed consent form used in the pilot study please see appendixes 2, 3, 4 respectively, for an overview of nursing homes recruitment procedures please see section 7.2.8.1.

The results of the pilot study are embedded in the analysis of the results of the main quantitative study (see chapter 8). However, the lessons learnt from the pilot study are below discussed.

7.2.7.3 Lessons learned from the pilot study

The recruitment phase of nursing homes during the pilot study was ineffective. For example, the study's formal invitation letters were not received, which may have negatively impacted nursing home response rates. In all cases the managers asked the researcher to forward all the study's documents by an e-mail. This thought to be an effective way to communicate the study to nursing home managers. In some other cases face-to-face visits were necessary for a meeting to be arranged. The response rates of the nursing homes remained low (one nursing home participated in the pilot study out of the seven initially approached). The pilot study highlighted the importance of building up relationships of trust with the nursing home managers in order for the cluster sampling process to be more effective. The nursing literature indicated that in some instances incentives are needed (Asch *et al.*, 2000). A research protocol was developed in order to increase nursing homes recruitment rates (section 7.6.3.1).

The procedure of participants' recruitment was effective. The nurses were approaching the residents who met the study's eligibility criteria and were asking for their permission for the researcher to talk to them. This again evidenced the importance of relationships of trust and familiarity in the process of data collection. After permission was granted, the nurses introduced the researcher to the participant. The researcher then explained the study to the participant, and administered to her/him the participant information sheet, and the informed consent form. In most cases the participants had difficulties in reading the participant information sheet by themselves. In these cases the researcher read the participant information sheet out loud to the participant. After the participant was informed through the participant information sheet, informed consent was obtained. All participants had the ability to provide written informed consent. The implementation of the questionnaire survey was a time consuming process. The researcher visited the nursing home 4 times in order to collect all set of data. One way of dealing with the long process of the administration of the questionnaires was the utilisation of a strategic plan of recruitment, for example categorising recruitment procedures by areas, location and distance.

The pilot study also revealed the time needed in completing the study's questionnaire. The average time of completion was 35 minutes, yet this varied from participant to participant and from situation to situation. That is, some of the interviews were interrupted because

participants needed to take their medicines, eat, take part in activities, smoke or simply because they were feeling tired to continue. However participants were willing to continue after some minutes had passed by. For example, one participant required 30 minutes to complete the questionnaire, and in another case the interview started at noon and finished two hours later. The majority of the participants were willing to fully complete the questionnaire. All the participants preferred the researcher to read out the questions loudly. The researcher read the questions to the participants, while they could follow up the questions being asked from a bigger format questionnaire. The same process was followed in the main study.

The pilot study also revealed that some questions were confusing for the participants, yet not sensitive, and thus they were re-phrased. For example, question 5 (on the pilot study's questionnaire) asked 'what is your ethnic group?' and requested the participant to specify his/her ethnic group; three out of six participants that fully completed the questionnaire asked the researcher for clarifications regarding the former question. The researcher in order to overcome any confusion regarding this specific question included a number of options so that participants could choose the option that fit them the most.

In addition, two other items from the VHIC scale could be thought as 'irrelevant to the study's population'. Specifically, item number 63, 'The well-being of my co-workers is important to me', and item number 65 'If a co-worker gets a prize I would feel proud' could be perceived as irrelevant since the older adults in nursing homes sampled in this study are not employed. The researcher however did not remove these items and included them in the analysis. The researcher did not drop the two items because she did not want to jeopardise the reliability and validity of the original scale. Also, the full version of tool has already been used among populations with no and/or low work experience. For example, Oppenheimer (2004) utilised the 32-items VHIC scale to compare cultural orientations between 'secondary school pupils' and University students, with an age range 12->22. The author utilised the full version of the VHIC scale without making any changes and/or amendments. The majority of students may not be familiar with work environments because of their young age but, even if they do work, they may not have enough experience from which we could draw conclusions. On the other hand the majority of older adults, despite not currently working, had previous work experience. It was thought, therefore, that older adults can adequately reply to these items. Another option was to re-phrase the questions, for example using past tense. However the effectiveness and appropriateness of the questionnaire tool was pilot tested, and no

problems were identified and/or emerged in relation to the above to items. Also the researcher, by including the items, was able to continue watching for any problems that may have been aroused as the study progressed. In any case that concerns did arise I would have retrospectively excluded the items from the quantitative analysis. If however these items were excluded during data collection the option of retrospective exclusion during analysis would not have been available. There were no indications and/or identified problems regarding the items during the pilot study. The items were not therefore excluded from the analysis for three main reasons: a) the pilot study did not rise any concerns in relation to these items, b) the tool has been previously used among populations with no and/or limited work experience, c) unwillingness to jeopardise tool's validity and reliability, and d) the option of potentially retrospectively excluding data from these items during data analysis would not have been available. The researcher revised the main study's questionnaire tool according to the lessons learnt from the pilot (please see appendix 7 for an overview of the revised questionnaire tool).

Conversations with the nurses revealed that the interRai-LTCF screening tool was easy to complete, straight forward and effective. The tool is based on coding for each statement, and thus allows assessments to take place in a short period of time. The average time of assessment was 5 minutes for each participant. Nurses were willing to complete the screening tool, yet they were worried about spending important working time on non-related providing care tasks. One-to-one time spent with the nurses during the assessment procedures seemed to minimise this issue. The analysis of the data collected by the screening tool highlighted the existence of some redundant screening statements (e.g. the periodic disordered thinking and awareness, the acute change in mental status and the change in decision making). However, the researchers did not wish to jeopardise the quality of the assessment tool, and therefore she did not remove the former items.

The screening tool was administrated by the researcher to the nurses, and carers of the nursing home. The researcher spent time with the nurses willing to complete the assessments and explained how the screening tool should be completed. The researcher stayed with the nurses for as much time as it was necessary. However, the overall process took approximately 10 to 15 minutes. As stated earlier nurses thought that the tool is straight forward and easy to complete. Overall, the administrative process of the assessment tool was effective, however, during the main study more one-to-one time was spent with the nurses.

The pilot study gave valuable lessons in relation to important aspects of this study. As stated earlier one significantly problematic area that needed further consideration was the nursing homes recruitment. The low response rates of nursing homes during the pilot study along with the lessons learnt from it (the quantitative pilot study), lead to the development of a protocol of recruitment. The protocol of recruitment proposed a ‘multi-method’ approach to nursing homes recruitment and was used during the implementation of the main quantitative phase. The ‘multi-method’ approach is below discussed.

7.2.8 A new ‘multi-method’ approach to nursing homes recruitment

Systematic reviews within the nursing literature highlight the need for more research in these settings (Oliver *et al.*, 2005), in order to understand the needs of this population. However, methodological and recruitment challenges burden the implementation of research studies (Hall *et al.*, 2009) in these settings. The findings of the pilot study seem to support this claim. In overcoming the recruitment challenges during the main study a new recruitment protocol was developed and followed. The aim of the protocol was therefore to positively affect and potentially maximise nursing homes response rates through the implementation of a ‘multi-method’ recruitment approach. This section, therefore, discusses the recruitment challenges during the pilot study, draws upon previous implemented recruitment strategies in the literature, and finally proposes a ‘multi-method’ approach to nursing homes recruitment.

7.2.8.1 Procedures and challenges of nursing homes recruitment during the pilot study

The eligible nursing homes in the origin of Bedfordshire were identified through the comprehensive and updated nursing home list (section 7.2.1). Seven eligible nursing homes were selected to participate in the pilot study. The researcher posted formal invitation letters to the manager of each selected nursing home (appendix 6). The formal invitation letters provided key information about the researcher’s role, the aims of the study, the study’s implications, and invited them to a meeting. The study’s Ethical approval letter was also included in the letter (appendix 5). Four days later the researcher contacted the nursing home managers via the phone. The phone calls aimed to ask nursing home managers if they received the invitation letters, and if they were willing to meet with the researcher. The phone calls also aimed to inform the nursing home managers about the study, in case they have not

yet received the posted invitation letters. The researcher also asked the managers to a meeting.

In four cases the managers could not be reached on the phone because he/she was busy (meetings, training sessions, nursing tasks being performed), while in the other three cases the administrator/receptionist refused to direct the phone call to the manager. In these cases contact details and a message asking the manager to return contact when convenient were left with the administrator/receptionist. Two days later another follow up phone call was made to six managers who had not returned contact (one manager did return contact). After several days of follow up phone calls, the researcher got into contact with four nursing home managers each of whom stated that they had not received the original invitation letter and requested that all of the documents be forwarded to them via e-mail. These emails were immediately sent; however 3 days later no return contact had yet been made by any of these managers. Over the next 3 weeks two out of the four managers phoned back to decline participation in the study. Both of these managers stated that they were involved with many internal procedures, and, therefore, they could not support the study. The other two managers did not return contact. Overall, the use of this recruitment strategy resulted in only one nursing home being successfully recruited. However, this was very likely because the researcher had prior direct contact with the manager of this nursing home. All the above recruitment challenges are well-documented in the nursing literature (e.g. Grady, 2001; Maas *et al.*, 2002; Hall *et al.*, 2009; Tzouvara *et al.*, in press).

7.2.8.2 Implemented strategies for increasing care homes recruitment

Previous contact with care providers and relationships of trust through a respectful and trustworthy manner is one key strategy that could potentially minimise fear and mistrust, and therefore increase care homes recruitment. In this study, the only nursing home that was successfully recruited involved a nursing home manager that had already previously formed a relationship of trust with the principal researcher. Asch *et al.*, (2000) in a review of 16 health care studies involving physicians revealed that doctors were more likely to agree to participate if they personally knew the recruiter, while there was a significant increase in participation rates if the recruiter was their friend (95%). McNeilly *et al.*, (2000) in a review of recruitment challenges and strategies of community based African-American participants, highlighted that key to an effective recruitment strategy are relationships of trust between researcher and those being researched. In a large randomised control trial Zermansky *et al.*,

(2007) examined the successful recruitment strategies of older adult in nursing homes. The authors argued that developing relationships of trust through regular visits and meetings with care providers, providing clear and key information about the background and outcomes of the project, and acknowledging care staff time and contribution are effective strategies in maximising care homes participation. Hanson *et al.*, (2010) examined the efficacy of a decision aid in supporting the choice between tube feeding and assisted oral feeding among older adults suffering from dementia in US-based nursing homes. The researchers based their recruitment strategy on prior contacts with nursing homes providers, on the utilisation of techniques that did not cause inconvenience to staff members and on a respectful approach. Twenty four out of the 29 initially approached nursing homes participated in the study. However, solely relying upon prior contacts with nursing home providers may not be sufficient. Researchers therefore need to implement a combination of effective recruitment strategies to help increase recruitment rates of care homes.

Being clear about study procedure and implementation and integrating staff in the research project are also potential effective strategies. Garcia *et al.* (2013) agrees, arguing that a successful care home recruitment process relies on “the involvement of nursing home administrators in the development of the research study (p.138)”. Staff members are more likely to participate and actively work with the research team when they feel they are an integral part of the study’s overall success. Researchers, however, need to ensure that they are not over-burdening care staff with study’s procedures and that they respect their time and contribution.

Another widely used recruitment strategy that has been found to maximise participation in health research (Maas *et al.*, 2002; Gyll *et al.*, 2003), and also helping to show respect for the participant’s time and contribution (Grady, 2001) is the use of incentives. In a meta-analysis of 39 studies using incentives Singer *et al.* (1999) found that: a) incentives maximise response rates in telephone and face-to-face surveys, b) prepaid incentives report no significant difference in response rates compared to conditional incentives, c) non-monetary incentives are less effective than monetary ones, and d) overall, incentives have significantly greater effect in studies where the initial response rates were low (cited in Börsch-Supan *et al.*, 2013). In the ageing literature, a wide range of incentives have been previously implemented. For example, Mody *et al.*, (2008) argue that providing non-monetary incentives such as certificates or plaques of study involvement, cards and gift baskets near holiday times, and lunch meetings or breakfast to care staff members can be an effective strategy in

increasing recruitment rates. Voyer *et al.*, (2008) argued that the use of certificates positively influenced their, overall, participant retention (86%), in a longitudinal study of mental health and psychotropic medication among Canadian older adults in retirement homes. Similarly, Goodman *et al.*, (2011) in a longitudinal study of older adults residing in UK-based care homes provided participating staff gift vouchers which boosted recruitment and retention rates. Therefore, it is clear that when participants feel valued and appreciated for their time and contribution, and mistrust and fear is minimised recruitment can - in principle - be boosted.

Therefore, overall, an examination of the literature highlights that building up relationships of trust with staff, following up on previous relevant participant contacts, valuing participant contribution by employing monetary and/or non-monetary incentives are effective methods towards increasing care home recruitment.

7.2.8.3 A proposed “multi-method” recruitment approach

Based on the previously implemented recruitment strategies and, the lessons learnt from the pilot study a ‘multi-method’ approach was proposed. More specifically, non-monetary incentives were offered to nursing home managers and staff members. The non-monetary incentives involved certificates of involvement (appendix 8). Certificates were both administrated to nursing homes, and to staff members completing residents’ assessments. The researcher by administrating certificates of involvement demonstrated her appreciation to the staff members’ time and contribution. The same process has previously been followed by several researchers (e.g. Mody *et al.*, 2008; Milligan *et al.*, 2014). The non-monetary incentives also involved the administration of juice and biscuits during the meetings with staff members, and the formal acknowledgement of the participated nursing homes in published research articles.

Face-to-face visits in the nursing homes were one key follow up procedure. The researcher by visiting each nursing home aimed to establish relationships of trust with the nursing home managers and the participants. According to the NIHR School for Social Care Research (2011) “good relationships are crucial and that the time invested in getting to know individuals at a personal level may ensure that people feel comfortable to participate and are willing to share their time and energy, contributing to a successful outcome” (p. 9). Face-to-face contact also revealed researcher’s good will to familiarise himself/herself with the

setting under examination, and researcher's commitment and dedication to the study. Face-to-face visits, finally, allow both parties (researcher and managers) to have a quick friendly conversation about the study. This might trigger the managers' interest to contact the researcher in a meeting for further details.

As stated earlier, a random control trial by Hanson *et al.* (2010) based the study's retain and recruitment procedures solely on the investigators previous contacts with nursing home providers. This highlights the significant role of previous contacts and personal experience to nursing homes recruitment. The researcher of this study, however, lacked previous experience and contacts with nursing home providers, in the area of Bedfordshire. The Faculty of Health and Social Sciences, in the University of Bedfordshire was asked to advance nursing homes recruitment, in this study, through the links and personal experience of members of the Faculty (particularly the Department of Health Care Practice and the office of Pre-Registration Nursing Practice Placements) with nursing home providers in the area of Bedfordshire. Also the Faculty co-operates with several nursing homes in the area of Bedfordshire for training and students' placement purposes. The involvement of people with personal relationships with nursing home providers was thought to maximise recruitment.

The 'multi-method approach' followed in the main study's quantitative phase involved three key stages: a) the administration of non-monetary incentives to nursing homes and staff members, b) the establishment of relationships of trust through face-to-face visits, c) the involvement in the study of people with previous personal contact, and experience with nursing home providers in the area of Bedfordshire. The latter was achieved through the Faculty of Health and Social Science, in the University of Bedfordshire. The 'multi-method' approach aimed at maximising nursing homes recruitment.

7.3 Recruitment procedures during Phase 1

In this section the procedures of recruitment of the quantitative phase are discussed. The process of recruitment is based upon the proposed 'multi-method' approach to recruitment introduced earlier (section 7.2.8.4). The section is divided into two distinct parts. The first part presents and discusses the procedures of nursing homes recruitment. The second part discusses the procedures of participants' recruitment.

7.3.1 Nursing homes recruitment procedures

The nursing homes of older adults in Bedfordshire were identified through a ‘nursing homes list’ (the ‘nursing home list’ is thoroughly discussed in section 7.2.5). Nursing homes were contacted and followed between April-October, 2014.

The manager of each nursing home was initially contacted via a formal invitation letter. The same strategy has previously been applied by several researchers (e.g. Randhawa & Stein, 2007). The role of the researcher, the aims of the study, and the reasons why the manager has been contacted were explained in the letter. The manager was invited to contact the researcher (via an e-mail or telephone) in order a meeting to be arranged. The researcher’s contact details were included in the letter (both written in the letter & the researcher’s business card), in order for the manager to be able to contact her. In addition a copy of the letter of the study’s Ethical approval was included. Follow up procedures followed, four days after the formal letters were sent. That is, the researcher face-to-face visited every eligible nursing home in Bedfordshire. The visits had a twofold aim: a) to establish relationships of trust between the researcher and the nursing home managers, and b) to inform the managers about the study, and invite them in a face-to-face meeting, in the case that they had not received the letters. Nursing home face-to-face visits lasted three days. Nursing homes with large capacity were visited first, while smaller nursing homes followed. Managers were not always available to have a quick chat with the researcher about the study. In other cases the managers were on annual leave, maternity leave, or currently out of office. The researcher re-visited the nursing homes in which managers were out of office, and/or on annual leave. When the researcher met the managers, she introduced herself and asked the managers whether they had received the study’s information letter. In those cases that the managers were familiar with the study, through the invitation letter, they were asked to have a meeting with the researcher. In the cases that managers were not familiar with the study, the researcher informed them about the study, gave them an envelope with the invitation letter, and ethics approval letter, and then asked them in a meeting to further discuss the details. It is worth mentioning that four large nursing homes (in terms of capacity) were visited by the researcher three times each. The last visited was in September 2014.

Follow up procedures also involved phone calls to nursing home managers. The researcher waited two days after the visits to phone all the managers who were unable to talk to her

during the visits. Nursing home managers that spoke with the researcher on the phone asked her to forward the study's information documents through an e-mail. The researcher immediately e-mailed the information documents. It is worth mentioning that even when managers had received the posted invitation letter, they still wished the documents to be forwarded to them via e-mails. Follow up phone calls were ineffective. The phone was answered by different individuals every time (e.g. nurses, carers, cooks). The researcher had to introduce herself every time, and ask the person to direct the call to the manager. In the cases that the phone was directed to the managers, they usually did not answer the phone. In other cases the researcher left messages for the manager with the person answered the phone. However, it is uncertain whether they passed the information to the managers or not. Managers did not return calls. The researcher managed to talk to the managers only when they would answer the phone. Follow up phone calls turned to be a slow and time consuming process.

Meetings between the managers and the researchers were essential. The meetings aimed at providing detailed information about the study procedures, time frames, and aims. During the meetings the managers were informed about the interRai-LTCF screening tool (section 7.2.4.1), and the non-monetary incentives (section 7.2.8.4), and the researcher had the opportunity to clarify any questions. The majority of the managers wished to take some time to think about the study, and reply via an e-mail or phone call whether they would permit access or not. Only a few managers agreed to provide access right after the end of the meeting. Managers who wished to reply later within the week, were more likely to deny participation.

Once the manager agreed to participate, a convenient time was arranged for the researcher to meet the nurses (and other staff members e.g. carers), and explain to them the interRai LTCF tool, and its process. That is, how they should complete the tool, so that they were able to provide accurate information. The researcher also spent as much time as it was needed for the nurses to comprehend the tool, and the process of completing it. The researcher also had the opportunity to clarify any questions. The researcher offered juices and biscuits during the meetings with staff members. The paper-based assessment tools were provided by the researcher. Once the assessments were completed, the researcher administrated certificates of participation both to nursing homes provided access, and staff members completing the tools.

Some of the managers were cancelling meetings and did not wish to reschedule. Also the assessment tools took quite a long time to be completed by the nursing homes, although there was an agreed deadline from both sides (researcher and staff members). For example, in one case the assessment tools were given to the staff members in May 2014, and were completed in August 2014, while the deadline was in June 2014. Overall, the process was time consuming, and expensive. The researcher spent 5 months, and £ 204 (the amount refers only to travel expenditures) in the recruitment phase. However, only six nursing homes were successfully recruited at the end of the recruitment phase (section 8.1).

7.3.2 Participants recruitment procedures

Once the assessments were completed, the data were then analysed. This was a significant step for identifying the eligible participants according to this thesis inclusion and exclusion criteria.

The recruitment of the residents was as follows: Nurses approached the eligible participants and asked their permission for the researcher to talk to them. This was applied for two main reasons: a) participants went under less stress as a familiar person initially approached them, and b) an appropriate time was arranged in order the face-to-face survey to be implemented. Most of the participants agreed to see, and talk to the researcher the same day and time, after they were approached by the nurses. In the cases participants wished to see the researchers another day, a convenient time and day to them was arranged. However, these cases were rare. Only two participants asked the researcher to visit them another day.

Participants who agreed to talk to the researcher were then informed about the researchers' name and role in the University. Then the participant information (appendix 9) sheet and informed consent form (appendix 10) were distributed to the participants. The participants were of old age, and thus the former forms were read out loudly by the researcher (in almost all cases). After the participants were informed, they were asked to voluntarily sign the consent form. At this point the researcher stressed (again) that the study was voluntary, anonymous, that the participants had the right to withdraw at any given time, and without providing any reason, that the data provided by the participants would remain confidential, and finally that participants could have breaks throughout the study, if they wished. Participants were asked whether they preferred the questions to be read out loudly to them by the researcher or not. All participants preferred the researcher to read out loudly the questions. The participants could follow the questions being asked through a bigger format

questionnaire, if case they wished to. However, none of the participants did so. The recruitment procedure of participants despite being effective was time consuming. Participants needed breaks in between the process because they were tired, wanted to eat, take part in activities, smoke or sleep. The researcher needed to visit each nursing home approximately four times to collect all set of data.

7.4 Ethical considerations

The main concern of this study is to be carried out in an ethical way. Participants completing a face-to-face questionnaire were first given a participant information sheet which explained all of the key information about the study, including why they have been asked to participate, how the data will be disseminated, and who will have access to the data. Participants agreed with this document, they were then asked to voluntarily sign the informed consent document which asks the participant to agree: a) that they fully understand what the research study is about, b) that they understand that participation is voluntary and that they can withdraw at any time, c) that they understand that the data collected will be treated with confidentiality, and that d) this study has ethical approval. Also participants were assured that data entered to the point of their withdrawal were destroyed, and, thus, not used in the final analysis.

At the end of the questionnaire, participants were asked to express an interest in participating in a follow up qualitative interview in the near future. If a participant agreed to take part in the interview, he/she was asked to provide their date of birth and name of nursing home on a separate sheet (appendix 11) so that to increase the likelihood of anonymity. The contact details of the researcher and the supervisor were given to the participants through the participant information sheet, so that if they wished, they could contact the researcher for any clarifications.

In addition, to help increase the likelihood of anonymity in this study, the questionnaires were anonymous and were coded using a unique ID number instead of the participant's real name. No names were collected during the quantitative phase, or other piece of information that would allow the researcher to track back the information provided to the participant. The likelihood of anonymity was also increased through the intermediate stage of the recruitment processes. As stated earlier, participants were initially approached by the nursing home staff. Therefore, the researcher had no access to names, or any information that could potentially reveal participants' identity. Although that the researcher had no access to names and could

not trace any information back to the participants, staff members might be able to recognise the identity of older adults who participated, which eventually jeopardises participants' anonymity. The researcher however used false names and age range, instead of participants' real age, in preventing identification and increasing anonymity. In addition specific phrases that could potentially reveal participants' identity have not been included in the thesis.

To ensure confidentiality in this study, all collected study data, I ensured that the data were stored securely (using password protected files), and that only myself and my supervisors had access to. More specifically, the completed paper-based questionnaires of the study were stored and secured in a locked cabinet in the researcher's office. Electronic data were saved in password protected laptops provided by the Institute for Health Research. The laptops in the Institute for Health research require an ID and password in order access to be gained. The password and ID are unique for each and every research staff and research project, and without knowing them access in the computers cannot be obtained. The files were protected by a unique password that only my supervisors and I had access to. Finally all data were encrypted using the University's of Bedfordshire software. All computers and laptops are protected by security software such as anti-virus programs which are regularly updated. All the above aimed at obtaining and guaranteeing confidentiality of the data collected in this study.

Knowing that this study examines a quite sensitive area, such as mental illness and among a vulnerable population such as older adults further considerations were taken into account. Participants were offered regular breaks when they were seemed to go under major stress. Also participants were asked if they wish to continue another day convenient to them, and/or withdraw from the study. Participants in general did not seem to be stressed and/or disturbed from the questions included in the questionnaire. However, the researcher after the questionnaire was completed spent time with the participants. The researcher and the participants were discussed anything the participants wanted to talk about. The latter aimed at emotionally discharging the participants who became stressed during the study. In an event of participants' great stress (although this did not happen during the implementation of the study) the researcher would have informed the nursing home staff members, and the nursing home manager.

Another key aspect of this study concerned potential safeguarding requirements and needs. According to the Department of Health (2014) "safeguarding means protecting an adult's

right to live in safety, free from abuse and neglect”. Safeguarding, therefore, is a key aspect for vulnerable populations such as older adults in care homes and long term care facilities who are at risk of experiencing abuse, neglect, and dignity. Although that the Department of Health has introduced a new law on adult safeguarding (Care Act 2014), there are numerous reported incidents of abuse and neglect on older adults residing in long term care facilities in the UK (Holt & Lee, 2014; BBC News, 2014; Dugan, 2014). Being aware that incidents of neglect and abuse may happen within long term care facilities, the researcher addressed potential safeguarding actions prior to the implementation of this study. In the case of an incident of neglect and/or abuse the researcher would raise and discuss the problem with her supervisors. However, the researcher would not reveal the name of the participant being abused and/or the name of the nursing home and/or any other information that could reveal participants’ identity. Following the conversation with the supervisory team, if viewed necessary, the researcher would raise an enquiry to the local authorities since they are responsible for carrying out a formal investigation in an adults’ case (AgeUK, 2015b, p. 12). According to the Care Act 2014 safeguarding process should be personalised. That means that “the wishes of the adult are very important, and that they should ‘experience the safeguarding process as empowering and supportive’” (AgeUK, 2015b, p 13). For example, if an older adult is mentally capable to decide about their relationships with other people and does not provide consent for the local authority to carry out an investigation, then it may not be possible to take the safeguarding enquiry any further. In the instance that an older person may lack the mental capacity to consent to a safeguarding enquiry, the decision about whether and how to proceed will be made by the local authority on the basis of what is in the person’s best interests (AgeUK, 2015b). In any of these cases, safeguarding recruitments were taking into account in this study, and in any incidence of abuse and /or neglect an enquire would have been filed to the local authorities. However, no incidence of abuse and/or neglect was identified during this study and therefore these protocols were not required.

The quantitative main study (Phase 1/questionnaire survey) gained ethical approval by the Institute for Health Research Ethics Committee, University of Bedfordshire (appendix 12).

7.5 Analysis of quantitative data

Analysis was performed using SPSS 19 version. The data was checked for missing values and normality. Histograms and the Shapiro-Wilk test for normality were used in checking the normal distribution of the data. The data was not normally distributed, and thus non-

parametric tests were performed. Missing values were replaced using the Expectation-maximisation algorithm (EM). The EM algorithm is an effective method in managing missing values (Schafer & Olsen, 1998; Moss, 2009). It is also preferable with small sample sizes and when more than 5% of the data are missing (Rubin *et al.*, 2007). The technique is based on the assumption that data are missing at random. To determine missing values randomisation the Little's Missing Completely at Random (MCAR) test was performed. The *p* values of the ISMI and VHIC scales was not significant ($\chi^2=147.7$, $df=196$, $sig=.996$; $\chi^2=41.6$, $df=320$, $sig=1$, $p=0.05$ respectively), and thus all missing data was missing at random. The small sample size of this study along with that more than 5% of the data were missing explain why the EM technique in managing missing values was used. However, missing values of the GHQ was counted as low scores. This method is the standard procedure to deal with GHQ missing values (GL-assessment, 2014). All missing values occurred due to the participants' unwillingness to respond.

Socio-demographic variables were categorised into groups. Specifically, marital status had two categories: single/separated/divorced/widowed, married; religiousness was grouped into two categories: atheist/not very religious, extremely/quite religious; and educational level was categorised into two groups: low educational level, high educational level. Loneliness was computed into two 'never/sometimes lonely', and 'often/always lonely' categories. Similar previously studies examining loneliness implemented the same technique (e.g. Victor *et al.*, 2005). Grouping data is common in research (e.g. Papadopoulos *et al.*, 2013; Victor & Yang 2012; Krajewski *et al.*, 2013). Data was grouped into larger categories so as to increase analytical power. The interRai-LTCF tool consists of 4 scales (Depression Rating Scale (DRS), Anhedonia Scale (ANH), Aggressive Behaviour scale (ABS), Cognitive Performance Scale (CPS)) (section 7.5). The cut-off point ≥ 3 was adopted for the DRS, ANH and ABS scale (Liang *et al.*, 2011; Ahn & Hordas, 2013) while the cut-off point of ≤ 3 was used for the CPS (Carpenter, 2006).

The ISMI scale was treated as a continuous variable. This method is common in the analysis of the former scale (e.g. Brohan *et al.*, 2010; Krajewski *et al.*, 2013; Boyd *et al.*, 2014). However it was also grouped into two categories: low stigma= ≤ 2.5 , high stigma= > 2.5 (Kazwieski *et al.*, 2013) in increasing power. The 'stigma resistance' subscale has been argued to examine conceptually different construct from the other subscales (Lysaker *et al.*, 2007; Brohan *et al.*, 2010). The main conceptual difference lies to the different aspects highlighted by this particular sub-scale. That is, it measures the levels of resistance that

people show towards the negative stereotypes against their mental illness, and not the actual stereotypes that they may internalise because of their mental illness. Therefore, stigma resistance does not explain and/or result to mental illness self-stigma, but it rather explains how people are resistant to stigma, and therefore they do not become self-stigmatised. The latter is key conceptual difference. Also the former sub-scale does not align with the self-stigma model adopted in this study. The self-stigma model aims at explaining mental illness internalised stigma through awareness, agreement, and finally endorsement of the negative stereotypes, and not through the resistance towards these stereotypes. Similar to other studies (e.g. Brohan *et al.*, 2010) the ‘stigma-resistance’ subscale was considered as conceptually different, and was therefore excluded from the analysis. Prevalence of self-stigma refers to the aggregation of the other 4 ISMI subscales. The 1/2 threshold for the GHQ was adopted (1 or less=no psychiatric symptoms, 2 or more=psychiatric symptoms). The latter threshold was adopted because of its high sensitivity (Cano *et al.*, 2001). Total collectivism scores were computed by aggregating the vertical collectivism (VC) and horizontal collectivism (HC) items. In the same direction, total individualism scores were determined by aggregating the vertical individualism (VI) and horizontal individualism (HI) items. Total individualism/collectivism scores were computed by subtracting the ‘total collectivism score’ from the ‘total individualism score’. Negative values indicated collectivism, while positive values indicated individualism. Vertical and horizontal individualism/collectivism (VIC/HIC) total scores were created to identify cultural differentiations among survey participants at the individual level. Total vertical individualism/collectivism scores (VIC) were determined by subtracting the ‘total vertical collectivism scores’ (VC) from the ‘vertical individualism scores’ (VI), while total horizontal individualism/collectivism scores (HIC) were computed by subtracting the ‘total horizontal collectivism scores’ (HC) from the ‘total horizontal individualism scores’ (HI). Negative values indicate VC orientations, while positive values indicated VI orientations. In the same direction negative values indicate HC cultural subscriptions, while positive values referred to HI subscriptions (Papadopoulos, 2009).

Frequencies and central tendencies were used in exploring percentages of distributions for psychiatric symptoms, loneliness, self-stigma and cultural values. As stated earlier non-parametric statistics were performed since data did not meet the assumptions for normality. Specifically, Mann-Whitney U test was used to test associations between two categorical independent variables (e.g. gender: male/female) and one continuous dependent variable (e.g. alienation). Spearman’s rho correlation test was utilised to examine associations between one

continuous independent variable (e.g. age) and one continuous dependent variable (e.g. social withdrawal). Such non-parametric tests are common statistical tests in examining associations between non-normally distributed variables (Pallant, 2007). The Chi square test for independence, and particularly the Fisher's exact probability test was used to examine significance between two categorical variables (e.g. gender and loneliness) (van Nood, 2013). Fisher's exact test is ideal with relatively small sample (McDonald, 2008), while it is preferable when there are less than 5 expected frequencies in any cell (Pallant, 2007). The Point-Biserial correlation test was used to establish associations between one independent continuous variable and one dependent categorical variable (Field, 2009). These tests were used to examine hypotheses 1, 2 and 3.

7.6 Summary

A face-to-face questionnaire survey under the context of a sequential mixed-method approach was used. The quantitative phase provides useful information about the prevalence of self-stigma, loneliness and participants' cultural subscriptions, while it addresses how other socio-demographic variables explain self-stigma and loneliness among this population (mentally ill older adults in nursing homes). For the needs of the study three hypotheses are formed.

For this study one key challenge is to define older adults, and identify eligible participants. Towards this line the interRai-LTCF assessment tools is used. A pilot study is implemented to address methodological and recruitment shortcomings. One key challenge identified is the barriers to the successful recruitment of nursing homes. The former challenge is not new within the nursing home literature. A protocol proposing a new 'multi-method' approach to nursing homes recruitment is proposed and followed in the main study.

Chapter 8 Phase 1: Quantitative results

This chapter presents the results of the quantitative survey. More specifically, this chapter presents the results of the nursing homes recruitment, the results of the LTCF assessments, the prevalence of loneliness and self-stigma, and participants' cultural subscriptions. The chapter also discusses whether and how socio-demographic and cultural factors explain levels of self-stigma and loneliness among older adults experiencing mental health problems in nursing homes.

8.1 Nursing homes recruitment

The nursing homes located in the area of Bedfordshire were identified through the 'nursing homes list'. As previously stated, this list of the nursing homes had recently been developed during another older adult care home health project in the county (see section 7.2.5).

Thirty four nursing homes were included in the list. Twenty seven invitation letters were sent to the nursing home managers for the needs of the main quantitative recruitment phase. The other seven nursing homes (out of the thirty four included in the list) had already been contacted during the quantitative pilot study (section 7.6). Follow up procedures revealed that 2 out of the 27 initial contacted nursing homes were shut down at the time of this study's recruitment process. Therefore 25 nursing homes could be involved in the recruitment phase of the main phase. Twenty five nursing home managers were contacted and followed up between April-October 2014 (section 7.7). Eleven out of the 25 nursing home managers agreed to have a meeting with the researcher. After the meeting, 6 out of the 11 nursing homes agreed upon participation. For a full breakdown of the nursing homes characteristics and recruitment results please see table 5 and 6 respectively.

Table 5: Results of nursing homes recruitment

Recruitment Process	Number of homes
Total Number of nursing homes approached	34
Nursing homes contacted in the pilot study	7
Nursing homes contacted in the main study	27
Nursing homes were shut down	2
Remaining nursing homes	25
Nursing homes agreed on a meeting	11
Nursing homes agreed on participation	6

Table 6: Characteristics of recruited nursing homes

Nursing homes	Number of residents at time of recruitment	Type of Ownership: Public/Private	Specialist/Non-specialist
Nursing home 1	28	Private	Specialist
Nursing home 2	85	Private	Specialist
Nursing home 3	60	Private	Non-specialist
Nursing home 4	36	Private	Specialist
Nursing home 5	40	Private	Specialist
Nursing home 6	26	Private	Non-specialist

8.1.2 Identifying eligible participants: the interRai-LTCF assessments

The interRai-LTCF assessment tool was administrated in each nursing home in identifying eligible survey participants (section 7.3.4.1, 7.3.1). The results of the interRai-LTCF assessments are presented into two sections. The first section presents the results of the assessments separately for each nursing home (table 7), while the second section presents the overall results of the assessments (table 8).

8.1.3 Results of the interRai-LTCF assessments per nursing home

The results of the interRai-LTCF assessments for each nursing home are herein discussed, and can be visually viewed in table 7.

Nursing home 1

The mental health well-being of 14 residents was assessed using the LTCF tool. Nine residents were males (64.3%) and 5 were females (35.7%) with a mean age 67.2 (SD=4.1, age range= 60-73). The majority of the residents had a medical record of mental illness (85.7%). The majority of the residents presented severe to very severe cognitive impairment (n=14, 64.2%, CPS= ≤ 3 , mean=4.2 \pm 2.8, min=0, max=8), depressive, anxious or sad mood (n=14, 92.6%, DRS= ≥ 3 , mean=8.0 \pm 4.9, min=2, max=19), and inability to experience pleasure from activities (n=14, 85.5%, AHS= ≥ 3 , mean=4.7 \pm 2.8, min=0, max=9). More than half of the residents reported high aggressive behaviour (n=14, 56.9%, ABS= ≥ 3 , mean=4.5 \pm 3.5, min=0, max=12). Five residents met the eligibility criteria (35.8%)

Nursing home 2

Forty seven residents were assessed through the LTCF assessment tool. Fifteen residents were males (31.9%) and 31 were females (66%). The mean age of residents was 83.7 (SD=9.6, age range= 65-99). The majority of the residents had a medical record of mental illness (63.8%). The majority of the residents suffered from severe to very severe cognitive impairment (n=47, 70.3%, CPS= ≤ 3 , mean=6.2 \pm 4.1, min=0, max=23). Almost half of the residents reported depressive, anxious or sad mood (n=47, 40.4%, DRS= ≥ 3 , mean=2.8 \pm 3.6, min=0, max=17), and inability to experience pleasure from activities (n=47, 44.7%, AHS= ≥ 3 , mean=2.3 \pm 2.2, min=0, max=11), while 34% of them presented high aggressive behaviour (n=47, ABS= ≥ 3 , mean=2.1 \pm 2.9, min=0, max=10). Fourteen residents were eligible to participate (29.8%).

Nursing home 3

Twenty nine residents were assessed through the LTCF assessment tool. Nine were males (31%), and 20 were females (69%), with mean age 79.5 (SD=12.1, age range=61-103). More than half of the residents had no medical record of mental illness (69%), while almost half of them presented severe to very severe cognitive impairment (n=29, 41.4%, CPS= ≤ 3 ,

mean=4.1±3.8, min=0, max=15), and depressive, anxious or sad mood (n=29, 44.8%, DRS= ≥3, mean=3.3±4.7, min=0, max=16). The majority of the residents were able to experience pleasure from activities (n=29, 72.3%, AHS= ≥3, mean=1.3±1.8, min=0, max=7), while they had low aggressive behaviour (n=29, 86.2%, ABS= ≥3, mean=0.7±1.6, min=0, max=6). Eight residents were eligible to participate (27.6%).

Nursing home 4

The mental health well-being of 11 residents was assessed. Three residents were males (27.3%) and 8 residents were females (72.7%). The mean age of the residents was 86.8 (SD=9.0, age range= 67-95), with the majority of them to be windowed (72.7%). All but one resident had no previous medical record of mental illness (90.9%). Almost all of the residents had intact cognitive function (n=11, 81.9%, CPS= ≤3, mean=1.6±1.7, min=0, max=5), and were able to experience pleasure from activities (n=11, 81.8%, AHS= ≥3, mean=0.3±0.9, min=0, max=3), while the majority of them did not present depressive, anxious or sad mood (n=11, 72.7%, DRS= ≥3, mean=3.5±6.4, min=0, max=17), and high aggressive behaviour (n=11, 90.9%, ABS= ≥3, mean=.30±.94, min=0, max=0). Two residents met the eligibility criteria (18.2%).

Nursing home 5

Twenty six residents were assessed through the interRai-LTCF assessment tool. Nine residents were males (34.6%) and 17 were females (65.4%) with mean age 85.4 (SD=6.5, age range=72-100). The majority of the residents had a medical record of mental illness (76.9%). The majority of the residents presented severe to very severe cognitive impairment (n=26, 77.1%, CPS= ≤3, mean=6.3±3.4, min=0, max=11), while they were able to experience pleasure from activities (n=26, 76.9%, AHS= ≥3, mean=1.4±2.3, min=0, max=9). More than half of the residents did not report depressive, anxious or sad mood (n=26, 57.7%, DRS= ≥3, mean=5.3±6.4, min=0, max=20). Low aggressive behaviour presented the 73.1% of the residents (n=26, ABS= ≥3, mean=2.3±3.8, min=0, max=11). Three residents were eligible to participate (11.5%).

Nursing home 6

The mental health well-being of 24 residents was assessed using the LTCF assessment tool. Seven residents were males (29.2%), and 16 of them were females (66.7%). The mean age of residents was 88.4 (SD=5.5, age range=78-97). The majority of the residents had a medical

record of mental illness (75%). The majority of the residents suffered from severe to very severe cognitive impairment (n=24, 75.1%, CPS= ≤ 3 , mean=5.7 \pm 3.1, min=0, max=10), while they did not report depressive, anxious or sad mood (n=24, 70.9%, DRS= ≥ 3 , mean=2.1 \pm 1.7, min=0, max=9). Almost all of the residents were able to experience pleasure from activities (n=24, 91.6%, AHS= ≥ 3 , mean=0.6 \pm 1.4, min=0, max=6). The 66.6% of the residents had high aggressive behaviour (n=24, ABS= ≥ 3 , mean =1.3 \pm 1.6, min=0, max=6). One resident met the eligibility criteria (0.04%).

Table 7: The interRai-LTCF assessments by nursing home

		Nursing home 1			Nursing home 2			Nursing home 3			Nursing home 4			Nursing home 5			Nursing home 6		
		N	%	Mean(SD)	N	%	Mean(SD)	n	%	Mean(SD)	N	%	Mean(SD)	n	%	Mean(SD)	n	%	Mean(SD)
Gender	Male	9	64.3	-	15	31.9	-	9	31	-	3	27.3	-	9	34.6	-	7	29.2	-
	Female	5	35.7	-	31	66	-	20	69	-	8	72.7	-	17	65.4	-	16	66.7	-
	Missing value	-	-	-	1	2.1	-	-	-	-	-	-	-	-	-	-	1	4.2	-
First language	English	14	100	-	47	100	-	29	100	-	11	100	-	26	100	-	24	100	-
	Other	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Marital status	Widowed	-	-	-	30	63.8	-	11	37.9	-	8	72.7	-	13	50	-	15	62.5	-
	Married	2	14.3	-	9	19.1	-	9	31	-	-	-	-	7	27	-	5	20.8	-
	Single	8	57.1	-	1	2.1	-	4	13.8	-	2	18.2	-	5	19.2	-	2	8.3	-
	Separated/Divorced	1	7.1	-	3	6.4	-	4	13.7	-	1	9.1	-	-	-	-	2	8.3	-
	Partner	2	14.3	-	-	-	-	1	3.4	-	-	-	-	1	3.8	-	-	-	-
	Missing value	1	7.1	-	4	8.5	-	-	-	-	-	-	-	-	-	-	-	-	-
History of mental illness	Yes	12	85.7	-	30	63.8	-	9	31	-	1	9.1	-	20	76.9	-	18	75	-
	No	2	14.3	-	16	34	-	20	69	-	10	90.9	-	6	23.1	-	6	25	-
	Missing value	-	-	-	1	2.1	-	-	-	-	-	-	-	-	-	-	-	-	-
Age		-	-	67.2 (4.1)	47	-	83.7 (9.6)	29	-	79.5	11	-	86.8 (9.0)	26	-	85.4 (6.5)	24	-	88.4 (5.5)
Age range		-	-	60-73	-	-	65-99	-	-	(12.1) 61-103	-	-	67-95	-	-	72-100	-	-	78-97
CPS*		14	64.2	4.2 (2.8)	47	70.3	6.2 (4.1)	29	41.4	4.1 (3.8)	11	81.9	1.6 (1.7)	26	77.1	6.3 (3.4)	24	75.1	5.7 (3.1)
Range		-	-	0-8	-	-	0-23	-	-	0-15	-	-	0-5	-	-	0-11	-	-	0-10
DRS**		14	92.6	8.0 (4.9)	47	40.4	2.8 (3.6)	29	44.8	3.3 (4.7)	11	72.7	3.5 (6.4)	26	57.7	5.3 (6.4)	24	70.9	2.1 (1.7)
Range		-	-	2-19	-	-	0-17	-	-	0-16	-	-	0-17	-	-	0-20	-	-	0-9
AHS***		14	85.5	4.7(2.8)	47	44.7	2.3 (2.2)	29	72.3	1.3 (1.8)	11	81.8	0.3 (0.9)	26	76.9	1.4 (2.3)	24	91.6	0.6 (1.4)
Range		-	-	0-9	-	-	0-11	-	-	0-7	-	-	0-3	-	-	0-9	-	-	0-6
ABS****		14	56.9	4.5(3.5)	47	34	2.1 (2.9)	29	86.2	0.7 (1.6)	11	90.9	.30 (.94)	26	73.1	2.3 (3.8)	24	66.6	1.3 (1.6)
Range		-	-	0-12	-	-	0-10	-	-	0-6	-	-	0-0	-	-	0-11	-	-	0-6

8.1.4 Overall results of the interRAI-LTCF assessments

The mental health well-being of 151 residents was assessed using the interRai-LTCF tool. Ninety seven residents were females (64.2%), and 52 were males (34.4%) with mean age 82.6 (SD=10.2, age range=60-103). Ninety residents had a medical record of mental illness (59.6%). The majority of the residents presented severe to very severe cognitive impairment (n=151, 61.6%, CPS= ≤ 3 , mean=5.3 \pm 3.7). Almost half of the residents were suffering from depressive, anxious or sad mood (n=151, 43.1%, DRS= ≥ 3 , mean 3.8 \pm 4.8), while a smaller number was unable to experience pleasure from activities (n=151, 33.1%, AHS= ≥ 3 , mean=1.8 \pm 2.3). The majority of the residents presented no to low aggressive behaviour (n=152, 70.8%, ABS= ≥ 3 , mean=1.8 \pm 2.8). Overall 33 residents met the eligibility criteria (n=151, 21.9%). For a full breakdown please see table 8.

Table 8: The overall results of the interRai-LTCF assessments

		N	%	Mean (SD, range)
Gender	Male	52	34.4	-
	Female	97	64.2	-
	Missing value	2	1.3	-
First language	English	149	99.3	-
	Other	1	0.7	-
Marital status	Widowed	77	51.0	-
	Married	32	21.2	-
	Single	22	14.6	-
	Separated/Divorced	11	7.3	-
	Partner	4	2.6	-
	Missing value	5	3.3	-
History of mental illness	Yes	90	59.6	-
	No	60	39.7	-
	Missing value	1	0.7	-
Age		151	-	82.6(10.2, 60-103)
CPS*		151	61.6	5.3 (3.7, 0-23)
DRS**		151	43.1	3.8 (4.8, 0-20)
AHS***		151	33.1	1.8 (2.3, 0-11)
ABS****		151	70.8	1.8 (2.8, 0-12)

* Cognitive Performance Scale= ≤3, ** Depression Scale=≥3, ***Anhedonia Scale=≥3, **** Aggressive Behaviour Scale=≥3

8.2 Response rates of survey participants

As stated earlier 33 residents out of the 151 initially assessed were eligible to participate in the study (21.9%). Of those 16 finally agreed upon participation (n=33, Rr=48.5%). Face-to-face communication revealed that respondents were more likely to have better physical and mental health than non-respondents. Unwillingness (n=33, 27.2%), worse physical health (n=33, 9.09%), hearing problems (33=9.09%), and hospitalisation (n=33, 6.06%) were the three main reasons for older adults' non-participation.

8.2.1 Socio-demographic background of survey participants

Sixteen residents participated in the survey. Of these 7 were males (43.8%) and 9 were females (56.3%). The mean age of the participants was 74.8 (SD= 9.5, age range=60-92). The majority of the survey participants described their ethnicity as 'white-English' and indicated English as their first language (87.5% respectively). More than half of the survey participants were extremely/quite religious (56.3%), had low educational level (75%), and perceived themselves as suffering from mental illness (68.8%). It is worth mentioning that although all survey participants were identified by staff members as mentally ill, 31.3% of them did not perceive themselves as such according to the results of the self-reported GHQ tool. Table 9 presents the socio-demographic details of survey participants.

Table 9: Socio-demographic details of eligible survey participants

Socio-demographic variables		N=16	%	Mean (SD)
Gender	Male	7	43.8	-
	Female	9	56.3	
Educational level*	High	4	25.0	-
	Low	12	75.0	
Religiousness**	High	9	56.3	-
	Low	6	37.5	
Missing value		1	6.3	
Marital status	Separated/Widowed/ Single	11	68.8	-
	Married	5	31.3	
First language	English	14	87.5	-
	Other***	2	12.6	
Ethnic group	English	14	87.5	-
	Other****	2	16.2	
GHQ*****	No mentally ill health	5	31.3	1.6 (.47)
	Mentally ill health	11	68.8	
Age	Age range	60-92	-	74.2 (9.5)

*High=college/undergraduate/postgraduate, low=primary/secondary school, **High=extremely/quite religious, low=not very religious/atheist, ***Other=Dutch, Armenian, ****Other=Black, White other, *****GHQ=1/2 threshold.

8.3 Prevalence of self-stigma

Descriptive analysis was performed to determine prevalence of self-stigma among participants (objective 1). As can be seen in table 10, overall levels of stigma were below the cut-off point of 2.5 ($n=16$, $ISMI \leq 2.5$, $mean=2.4 \pm .40$). More specifically, 68.8%, scored below the threshold on the alienation subscale ($n=16$, $ISMI \leq 2.5$, $mean=2.4 \pm .49$), and discrimination experience subscale ($n=16$, 68.6%, $ISMI \leq 2.5$, $mean=2.4 \pm .62$), while 50% scored above the threshold on the social withdrawal subscale ($n=16$, $ISMI \leq 2.5$, $mean=2.3 \pm .51$), and 62.5% of them scored above on the stereotype endorsement subscale ($n=16$, $ISMI \leq 2.5$, $mean=2.56 \pm .40$).

8.3.1 Reliability scores of ISMI scale

Alpha-Coefficient tests were performed to examine the reliability levels of the ISMI constructs. Overall the ISMI scale reported a high level of internal consistency ($\alpha=0.87$). The results of the reliability subscales scores were: alienation ($\alpha=0.79$), stereotype endorsement ($\alpha=0.69$), discrimination experience ($\alpha=0.83$), social withdraw (0.75), and stigma resistance ($\alpha=0.83$).

8.4 Prevalence of loneliness

Descriptive statistics was performed to determine prevalence of loneliness among participants (objective 1). The majority of the survey participants reported that they were sometimes/never lonely ($n=16$, 68.8%, $min-max=1-4$) (table 10), while 12.5% of them perceived themselves as always, and often lonely ($n=16$, $min-max=1-4$). Prevalence of loneliness was grouped into two categories: never/sometimes lonely, and often/always lonely.

Table 10: Prevalence of self-stigma and loneliness among survey participants

ISMI Constructs	N	Mean	SD	Minimal/Low ≤2.5		Moderate/High ≥2.5	
				N	%	N	%
ISMI*	16	2.4	0.40	9	56.3	7	43.8
Alienation (A)	16	2.4	0.49	11	68.8	5	31.2
Stereotype Endorsement (SE)	16	2.56	0.40	6	37.5	10	62.5
Discrimination Experience (DE)	16	2.4	0.65	11	68.6	5	31.2
Social Withdrawal (SW)	16	2.3	0.51	8	50	8	50
Loneliness**	N	%	min-max				
				-	-	-	-
Never/sometimes lonely	11	68.8	1-4				
Often/always lonely	5	31.2	1-4	-	-	-	-

*ISMI cut off point = ≥2.5, **loneliness was categorised into two groups=never/sometimes lonely, often/always lonely

8.5 Cultural orientations: examining the I/C and HVIC cultural levels

The VHIC scale presented adequate internal consistency reliability ($\alpha=0.60$). The maximum collectivism score was -11, and the maximum individualism score was 3.50 (median -.5). More than half of the participants were found to subscribe to collectivistic cultural orientations ($n=16$, 50.3%). Figure 11, offers a visual examination of individualism/collectivism scores among survey participants.

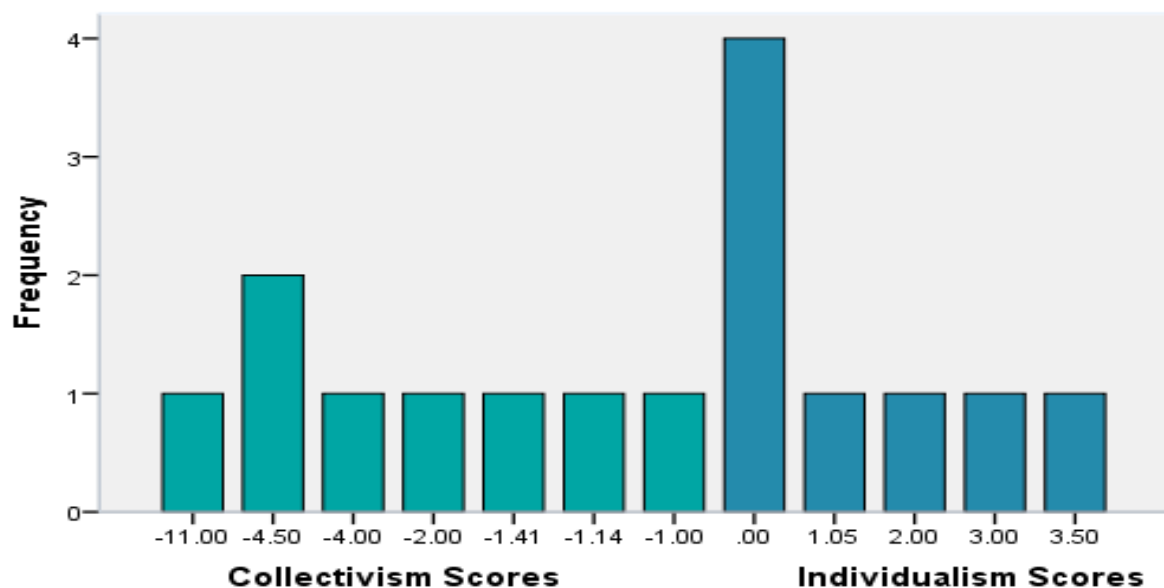


Figure 11: Bar chart of collectivism/individualism scores among participants

VIC scores ranged from -5.50 (highly VC) to 4.50 (highly VI), and HIC scores ranged from -1.50 (highly HC) to 6.50 (highly HI). The small sample size of this study did not allow any meaningful interpretation of the VHIC results, while it did not allow inferential analysis in relation to VHIC cultural constructs. Inferential analysis, and therefore hypotheses testing was performed in relation to I/C constructs.

8.6 Explanatory factors of ISMI and loneliness

8.6.1 Socio-demographic variables as explanatory factors of ISMI constructs

No significant relationships were reported between age, gender, religiousness, educational level, and ISMI constructs (see table 11 for a full breakdown). However there was a significant relationship between marital status and stereotype endorsement. Specifically, participants who were single/separated/widowed endorsed significantly higher levels of stereotypes compared to their married counterparts ($U=5$, sig. =.010, $p=0.05$).

Table 11: Socio-demographic variables and ISMI constructs

Socio-demographic Variables		ISMI Constructs								
		n	A*		SE***		DE***		SW****	
			MR	Median	MR	Median	MR	Median	MR	Median
Gender	Male	7	8.36	2.5	8.29	2.5	8.0	2.2	9.36	2.5
	Female	9	8.61	2.3	8.67	2.7	8.89	2.2	7.83	2.0
U			30.5		30.0		28.0		25.5	
Marital status	Single/Separated/Widowed	11	9.14	2.5	10.5	2.7	8.95	2.26	7.64	2.0
	Married	5	7.10	2.1	4.0	2.1	7.5	2.26	10.4	2.5
U			20.5		5.0		22.5		18.0	
Educational level	High+	4	10.38	2.6	8.75	2.6	11.0	2.5	10.63	2.66
	Low++	12	7.88	2.3	8.42	2.6	7.67	2.2	7.79	2.08
U			16.5		23.0		14.0		15.5	
Religiousness	Extremely/Quite	9	7.94	2.3	8.72	2.7	8.94	2.2	9.83	2.6
	Not very/Atheist	6	8.08	2.4	6.92	2.3	6.58	2.1	5.25	2.0
U			26.5		20.5		18.5		10.5	
		ISMI Constructs								
		n	A		SE		DE		SW	
			rho		Rho		rho		rho	
Age		16	.183		.045		.027		-.101	

*=alienation, **=stereotype endorsement, ***=discrimination experience, ****= social withdraw, +=college/undergraduate/postgraduate, ++=primary/secondary school, p=0.05

Tests performed: Mann-Whitney U test, Spearman's Correlation

8.6.2 Socio-demographic variables as explanatory factors of loneliness

As can be seen in table 12, there was no significant association between loneliness, gender, marital status and educational level. However, loneliness was significantly correlated with religiousness (sig.=.044, $p=0.05$). Specifically, participants who are quite/extremely religious are less likely to endure feelings of loneliness. Also there was a significant correlation between loneliness and age ($r=.476$, sig.=.062, $p=0.05$). The results indicated a positive association between variables. Therefore, loneliness is likely to increase with age.

Table 12: Socio-demographic variables and loneliness

Socio-demographic Variables		Loneliness		
		Never/Sometimes lonely n (%)	Often/always lonely n (%)	p-value*
Gender	Male	5 (71.4)	2 (28.6)	1
	Female	7 (77.8)	2 (22.2)	
Marital status	Single/Separated/Widowed	8 (72.7)	3 (27.3)	1
	Married	4 (80)	1 (20)	
Educational level	High+	3 (75)	1 (25)	.728
	Low++	9 (75)	3 (25)	
Religiousness	Extremely/Quite	9 (100)	0	.044
	Not very/Atheist	3 (50)	3 (50)	

*Fisher's exact test: p=0.05, +=college/undergraduate/postgraduate, ++=primary/secondary school

8.6.3 Inter-relationships between self-stigma and loneliness

Objective 4 of this study aimed at examining the conceptual inter-relationships between self-stigma and loneliness (hypotheses 1). That is, to identify the inter-relationships between loneliness and self-stigma among older adults experiencing mental health problems in nursing homes.

In addressing objective 2, one hypothesis was formed:

Hypotheses 1

There is an inter-relationship between self-stigma and loneliness among older adults with mental health problems in nursing homes.

No significant associations between self-stigma and loneliness were reported with the results indicating a negative correlation ($r = -.177$, $\text{sig.} = .512$, $p < 0.05$). Higher self-stigma scores are associated with lower loneliness scores. Hypothesis 1 was therefore not supported by the findings.

8.6.4 I/C as an explanatory factor of self-stigma and loneliness

Objective 4 of this study aimed to identify how and whether the individualism/collectivism cultural orientations explain self-stigma and loneliness (Hypotheses 2, and 3).

In examining objective 3, two hypotheses were formed:

Hypothesis 2:

Older adults experiencing mental health problems in nursing homes and value collectivism are more likely to experience both self-stigma and loneliness.

No significant relationship between internalised mental illness scale constructs and collectivism orientations was reported. In addition there was no significant relationship between collectivistic values and loneliness. Hypothesis 2 was therefore not supported by the findings.

Hypothesis 3

Older adults with mental health problems in nursing homes and value individualism are less likely to experience both self-stigma and loneliness.

The analysis did not indicate any significant relationship between individualistic cultural orientations, self-stigma and loneliness. Similar to above, therefore, hypothesis 3 was not supported by the findings. The following sections provide a discussion for the above findings.

8.7 Discussion of the quantitative results

This section discusses the findings of the quantitative study. It begins with a discussion of the prevalence of self-stigma among this population, and whether and how socio-demographic factors and insight into one's illness, explain levels of self-stigma among them. A discussion regarding the levels of loneliness and how and whether socio-demographic factors explain loneliness follows. The section links this study's findings with previous literature, and highlights its potential connection with existing policies and strategies. The section ends with a discussion of participants' cultural orientations, and their inter-relationships with loneliness and self-stigma.

8.7.1 Self-stigma among mentally ill older adults in nursing homes

More than half of this study's participants reported low levels of self-stigma (56.3%), while a substantial number of them scored high on the self-stigma scale (43.8%). The findings emphasize the need to systematically examine how this population views and perceives their mental illness. Specifically in this study, 68.8% of the participants perceive themselves as less valuable members in the community, while almost the same proportion (68.6%) experience discrimination because of their illness. Desire for social isolation was high among half of the participants (50%). Finally, 62.5% of them endorsed high levels of stereotypes towards mental illness. This aligns with the self-stigma model adopted in this study, and more importantly points out the key role of stereotypes in the process of self-stigma. However, the above findings should be viewed with caution because of the small sample size of this study (n=16). The findings, therefore, cannot be generalised to the target population.

The findings of this study reveal that older adults experiencing mental health problems become self-stigmatised. This aligns with previous empirical evidence in the self-stigma literature. For example, Werner *et al.*, (2008) examined the relationships between self-stigma and self-esteem among a sample of inpatients older and younger adults with schizophrenia

(n=86). The authors revealed that levels of self-stigma are moderate across all age groups with the older participants reporting lower levels of self-stigma. Another study by Werner *et al.*, (2009) reports similar findings. The authors examined self-stigma and its correlates among Israeli older adults diagnosed with depression (n=54, mean age=74). The findings of their study indicated that self-stigma does exist among this population. In a UK-based study Griffiths (2008) explored experiences of self-stigma among 14 older adults utilising mental health services (age range=65-92) from three different geographical areas. The author found that stigma was present, yet participants reported low levels of mental illness stigma. One key aspect of the above studies is that they examined mental illness stigma either among outpatient mentally ill older adults or among psychiatric inpatients older adults. This study, however, examined self-stigma among UK-based older adults with mental health problems in nursing homes, and therefore provides insights into levels of self-stigma among this population. The latter is one key implication of the findings of this study since they advance our understandings on self-stigma and provide the platform for further investigation on the topic. This is significant both because of the increasing number of older adults with mental health problems in the UK (Department of Health, 2011), and the limited number of studies examining self-stigma among older adults within the UK context.

Despite the small sample of this study, the results offer some important theoretical implications. As stated earlier, this population presents high levels of social withdrawal, while they are prone to alienation. It is important here to highlight the potential effects of self-stigma on experiences of loneliness. The findings indicate the theoretical relationships between older adults' loneliness and self-stigma. Older adults experiencing mental health problems become self-stigmatised, perceive themselves as inferior, deny social participation by withdrawing from social activities, and therefore become lonely. This is important given the findings of this study which report that loneliness is a real problem among this population (see chapter 10). It is therefore significant to start considering how self-stigma, through alienation and social withdrawal, contributes to experiences of loneliness, and to develop a new theoretical conceptualisation that explains the potential theoretical inter-relationships between self-stigma and loneliness.

The findings also highlight a key shortcoming in relation to the implemented mental health policies and strategies in the UK. Specifically, the '*No Health without Mental Health*' strategy aimed to improve the mental health and wellbeing of the population, and the outcomes for the mentally ill through high-quality services that are equally accessible to all

(Department of Health, 2011). The strategy sets out clear aims in relation to the psychological well-being of people experiencing mental health problems. However, it fails to specifically address the needs of mentally ill older adults in care homes. This is highly concerning given that their needs are different, unique and quite complex compared to community-based adults. Yet their needs are often being neglected by the majority of government's mental health policies and strategies. The same shortcoming was also noticed in the 2014 mental health policy '*Closing the gap: priorities for essential change in mental health policy*'. National strategies that meet the needs of older adults with mental health problems in care homes are limited, and often address to specific mental health problems among them (e.g. The National Dementia Strategy, 2009; Dementia Challenge, 2012b). This underestimates the potential negative effects of other types of mental illnesses in this population such as depression and anxiety. Without clear objectives of national policies and strategies that specifically aim to address and improve the psychological well-being of this population, it is likely that levels of self-stigma will get worse among them.

The Department of Health works closely with the '*Time to Change*' anti-stigma campaign which was launched in 2007, and aims to tackle stigma and discriminating attitudes towards mental illness. *Time to Change* is one of the leading anti-stigma campaigns in the UK. Time to Change achieved an overall 6.4% improvement in attitudes towards mental illness in 2007, an overall 4.8% improvement in 2011, and a 2.8% improvement between 2012 and 2013 (Time to Change, 2015). Despite its tremendous impact the campaign mainly focuses on improving public attitudes towards mental illness. This is quite problematic for one main reason. It is unknown how institutionalised people with mental health problems perceive and feel about their illness, and how the public views and perceives people who are suffering from mental illnesses and residing in long term care facilities. Therefore we are unable to examine, report, and potentially improve levels of mental illness stigma among this population. It can be argued therefore that older adults experiencing mental health problems in long-term care facilities are, once again, underrepresented in national policies, strategies, and anti-stigma campaigns which may result to worse stigma levels among them.

The small sample size of this study does not allow for the findings to be generalised to the target population. However, the findings do provide an indication of how older adults with mental health problems in nursing homes experience self-stigma. The main implications of this study is that it adds to this body of research, both empirically and theoretically, highlights the need for more research on the topic, and the need to develop national mental health

policies and strategies that specifically target the mental health well-being of this population, and therefore their perceptions towards themselves.

8.7.1.1 Self-stigma and socio-demographic factors

No significant relationships were found between sex, age, educational level, and religiousness. This comes in line with Vrbová *et al.*'s (2014) study that also reports no significant correlations between socio-demographic variables (age, age of illness onset, gender, education, marital status, employment, duration of the illness, number of hospitalizations and antipsychotic dosage), and self-stigma in 90 Czech outpatients diagnosed with psychotic disorders. However, this seems to oppose previous findings on self-stigma literature which showed that self-stigma correlates with sex (Grant *et al.*, 2015), age (Krajewski *et al.*, 2013), educational level (Yen *et al.*, 2005), and religiosity (Quintana, 2013). The findings of this study did however reveal a relationship between marital status and self-stigma. Participants who were single/separated/widowed reported higher levels of self-stigma compared to their married counterparts. A study by Assefa *et al.*, (2012) reports similar findings. The authors examined levels of self-stigma among 212 Ethiopian psychiatric outpatients with schizophrenia. The findings showed that single patients endorse high levels of self-stigma. The literature review of this study and empirical findings have revealed that self-stigma negatively impact people's social relationships (Link *et al.*, 1989; Perlick *et al.*, 2001; Kleim *et al.*, 2008; Yanos *et al.*, 2008). Mentally ill single/separated/widowed older adults might have difficulties in forming adequate social networks which results to higher levels of self-stigma. Another potential explanation is that single/separated/widowed older adults lack intimate relationships, and thus emotional security. Therefore, the absence of a partner who often provides emotional security may result to higher levels of self-stigma. Also single/separated/widowed older adults might have no one close to them so that they can openly talk about their illness and/or to share their views and perceptions towards themselves.

The analysis of the findings did not identify any significant relationships between insight into illness and levels of self-stigma among this population. Also the limited number of studies on self-stigma and insight into illness among older adults makes comparisons problematic. However research on self-stigma across different age groups stresses out the significant relationship between mental illness insight and self-stigma. For example, Ehrlich-Ben *et al.*, (2013) examined the relationships between insight into illness, self-stigma, and meaning in life among 60 Israeli adults with mental illness (age range 20-89). The authors found a

positive correlation between mental illness insight and self-stigma, and a negative correlation with meaning in life. That is, higher insight into illness was significantly correlated with higher self-stigma levels, and less meaning in life. Insight into mental illness is therefore significant since it influences attitudes, perceptions, and coping mechanisms towards mental illness. The small sample size could partially explain why non-significant relationships between insight and self-stigma were identified in this study. Another explanation could be related to the care-home context. Older adults in nursing homes may have insight into their illness, however because they reside, communicate, and are around with people with similar and/or same conditions to them, it helps them to resist endorsing high levels of self-stigma. However it is worth mentioning here that 31.3% of the study's participants had no insight into their illness. It is possible that older adults are less likely to internalise negative perceptions towards themselves because they have no insight into illness. Therefore, they may not perceive themselves as less valuable members of the community which reduces the likelihood for self-stigmatisation.

In this study the statistical non-significant relationship between socio-demographic variables and self-stigma does not necessarily indicate the overall absence of their relationship. However, marital status was correlated with levels of self-stigma among this population. This is an important finding given the high number of older adults who are widowed (AgeUK, 2015). More research that examines and identifies marital status differences on self-stigma is needed to understand its key role on levels of self-stigma. The findings should be viewed with caution because of the small sample size of this study.

8.7.2 Loneliness among mentally ill older adults in nursing homes

The quantitative data analysis identified 68.8% of the study sample to perceive themselves as sometimes lonely, while 12.5% reported severe levels of loneliness. In line with previous empirical evidence, this study reveals that loneliness is key issue among this population. Yet the small sample size of this study does not allow claims for findings generalisation. Drageset *et al.*, (2011) examined levels of loneliness and social support among 227 long-term nursing home residents, in Norway. The findings revealed that 56% of the participants experience loneliness. A study by van Beljouw *et al.*, (2014), in a sample of 249 older adults with mental health problems also found that prevalence of loneliness was high among them (87.8%). In addition, a UK-based study by WRVS (2012) which examined levels of loneliness amongst 500 older adults (≥ 75 years old), also identified prevalent loneliness (75%). Research by

Victor and Bowling (2012) longitudinally examined levels of loneliness among British older adults (+65) over a 10-year period time. The findings revealed that 10% of them endure severe feelings of loneliness. The findings of this study report similar results in relation to severe levels of loneliness (12.5%). However Victor and Bowling's study examined levels of loneliness among community-based older adults.

Loneliness is a common issue among UK-based older adults in nursing homes. This has also been highlighted by recent UK strategies. For example, the White Paper '*Caring for our future: reforming care and support*' (Department of Health, 2012a) acknowledges the need for long-term care residents' social integration, and launches a number of strategies to improve residents' connection with community members. However the White Paper seems to disregard the multi-dimensional nature of loneliness, while seems to misinterpret loneliness with social isolation. These are two different concepts that should not be used interchangeably (see section 3.2.2). This is quite problematic given the findings of this study that identify loneliness as a real problem among this population, while the qualitative findings stress that both emotional and social loneliness (see section 10.6.1) are key issues among this age group. That is, both the quality and quantity of relationships matter. Therefore policies and strategies should aim to tackle loneliness, rather than aiming to exclusively reduce social isolation among this population.

Loneliness is a real problem and key issue among this population, and although we should view this study's findings with caution, they still provide preliminary empirical findings on the topic (given the limited knowledge on levels of loneliness among UK-based long-term care residents), set the platform for future research, and reveal a key issue among this population. This is highly important given recent findings that showed that loneliness significantly correlates with increase mortality rates among nursing home residents (Drageset *et al.*, 2013).

8.7.2.1 Loneliness and socio-demographic factors

The quantitative findings revealed a positive correlation between age and levels of loneliness. However, there is an inconsistency in the loneliness literature on whether and how age correlates with loneliness. There is a body of literature that suggests no age differences on levels of loneliness (e.g. Tesch-Römer *et al.*, 2013; Nicolaisen & Thorsen 2014), while there

are studies that reveal strong correlations between loneliness and age. Such an example is Dahlberg *et al.*'s (2015) study. The authors using a national longitudinal study (n=587) examined predictors and changes in loneliness among Swedish older adults (70+). The findings show that there are differences in levels of loneliness among older adults, with the prevalence of loneliness to increase with age. In the same line the ONS (2013) in a UK-national study measuring older adults' well being reveals that loneliness is more prevalent among the oldest age group. Specifically, almost 46% of participants aged 80 and over reported being often or sometimes lonely in comparison to almost 34% of all aged 52 years old and above. One possible explanation is the constant life changes that older adults endure and cope with. Losses, limited social interactions and inadequate social lives may negatively influence their feelings of loneliness. This is important and links with the theoretical implications discussed earlier in relation to the relationships between loneliness and self-stigma (see section 8.7.1). Poor mental and physical health could also explain increase levels of loneliness with age. With increasing age, poor health is also more prevalent. Frail older adults may become isolated due to their inability to interact with others because they are physically unable to do so. This may trigger feelings of loneliness to increase. The care-home context may also exacerbate feelings of loneliness among this population since older adults may feel they are far away, both physically and emotionally, from their previous environments. Finally, care homes' structure may cause loneliness to worsen. Older adults follow a very specific schedule in the nursing home, and have a specific daily routine. This may influence their emotional stability by increasing feelings of hopelessness, may decrease likelihood for continuous social interaction with other residents, and may negatively impact to the development and maintenance of close relationships.

Religiousness was found to correlate with levels of loneliness. The quantitative findings indicate that older adults who are quite/extremely religiousness are less likely to endure feelings of loneliness compare to their atheist/not very religiousness counterparts. The current findings therefore support earlier claims, that is, that religiosity can 'protect' from and buffer feelings of loneliness (Williams *et al.*, 1991), and give weight to previous empirical findings. For example Lauder *et al.*, 2006 in a sample of 1289 survey participants (18+) found that people without strong religious beliefs are more likely to feel lonely. It seems therefore that religiousness is a key coping mechanism towards experiences of loneliness among older adults in nursing homes. Harrison *et al.*'s (2001) systematic review on religious coping across various groups revealed that 30% to almost 80% of them utilise religion as a coping

mechanism. One possible explanation is that older adults in nursing homes wish and desire to maintain close relationships and interaction with others. Religiosity therefore may satisfy their yearn for closeness and connectedness through their close relationship with God.

Relationships between loneliness and other socio-demographic variables (sex, educational level, marital status) were not found to be statistically significant. This seems to oppose findings from previous studies that revealed significant relationships between loneliness and socio-demographic variables such as gender (Nicolaisen & Thorsen 2014), ethnicity (Victor *et al.*, 2002), and marital status (Dahlberg *et al.*, 2015). One explanation for the non-significant relationships between the former variables and loneliness might be the small sample of this study. The non-identification of significant relationships between socio-demographic variables and loneliness among this population does not necessarily mean the absence of a relationship. After all, as this study's findings have indicated, loneliness correlates with age and religiosity.

The findings are important because they provide grounds for further research on the topic, and pathways for re-thinking and potentially re-forming the theoretical conceptualisation of loneliness. Specifically, in relation to loneliness and age since the majority of older adults in nursing homes tend to be older, and have more complex healthcare needs (British Geriatric Society, 2011). In addition, the findings highlight the important role of age, and religiosity when developing policies and strategies for this population. However, the findings of this study should be viewed with caution because of lack of external validity, which is one of the key limitations of this study. In addition, the study sampled older adults who only speak and understand the English language. Therefore our knowledge about levels of loneliness and self-stigma among non-English older adults remains limited.

8.7.3 Cultural orientations and their inter-relationships with self-stigma and loneliness

The quantitative results indicate that collectivism was prevalent among this population (50.3%). The findings seem both to oppose theoretical suggestions (Triandis 2001) and empirical findings (Paxman, 1999; Sun, 2004; Hofstede, 2008; Willis 2012; Papadopoulos *et al.*, 2013). For example, Willis *et al.*, (2012) in a qualitative study explored cultural differentiations in care giving behaviour among five different cultural groups (White British, White Irish, South Asia). The findings revealed that White British participants were more

individually oriented, while they adopted an individualistic type of formal support behaviour. It is worth mentioning however that the majority of the studies do not distinguish their findings based on the individualism-collectivism model, while others do not adapt cultural assessment tools that directly measure individualism and collectivism cultural subscriptions. In addition, the majority of the studies examine cultural subscriptions at the cultural and not the individual level. The latter aspects make inferences problematic, while highlight the need for further investigation on the topic. It is worth mentioning, however, that this study suffers from low sample size, which make inferences problematic.

As stated earlier half of the study's participants were found to subscribe to collectivistic cultural orientations. One possible explanation lies in the older age of the participants who are possibly in a stage in their lives that prioritise and yearn for closeness and tight relationships with their family members. In addition the life changes they face (e.g. death, physical inabilities) may exacerbate their need for close family communication and interaction. Therefore, older adults may become vulnerable and thus more dependent (both physically and emotionally) in their families and in-groups. This suggests that the older people get the more family oriented they might become. That is the individually-oriented cultural self gives room to collectivistic-oriented cultural self (as people are getting older).

On the other hand, the care home setting itself could explain why older adults tend to be more collectivistic oriented. Being far away from previous environment, family members, and in groups may influence, and potentially exacerbates, notions of closeness and connectedness. Therefore older adults who are unable to fulfil these needs, because of the nursing home setting, become collectivistic-oriented. Also the care setting may influence perceptions about what is important to life. When older adults relocate to their new environment, that is nursing home, they may start appreciating aspects of life that until then were taken for granted, that is, family closeness, and in-groups connectedness. Therefore, the nursing home setting may influence collectivism to arise because of the changes that marks in older adults lives. Finally older adults may become collectivists simply because they reside in a nursing home. They are being together with peers suffering from similar physical and health problems, and probably start feeling close to others, and thus inter-connected to each other. The literature review of this study reveals cultural variations of loneliness and self-stigma prevalence (see chapter 5, section 5.2.3). The literature through empirical evidence therefore suggests that there is an inter-relationship between cultural orientations, loneliness, and self-stigma. The small sample of this study did not allow any inferential analysis to be performed in examining these inter-

relationships. Yet it is important to highlight that cultural differentiations on levels of self-stigma and loneliness are possible among this population.

8.8 Summary

The study lacks external validity because of its small sample size, which make inferences and generalisations to the target population problematic. However, the findings reveal that self-stigma exists among the sampled population, and although its overall levels were reported as low, a substantial number of older adults scored moderate/high on the self-stigma scale. The findings of this study align with the self-stigma literature. Self-stigma is a real problem among this population. However, the limited number of studies makes inferences problematic. Marital status correlates with levels of self-stigma, however no significant correlations were found between self-stigma and several socio-demographic factors (sex, age, educational level, religiousness). The findings also reported no significant relationship between self-stigma and insight into illness; a well-established factor within the self-stigma literature. The findings are important because they provide empirical and theoretical developments on the topic, highlight the need for more investigation, and emphasise the need to re-form, and potentially develop, national mental health policies and strategies that specifically target the mental health needs of this population.

The quantitative results reveal that loneliness is a common issue among this population. This comes in line with the loneliness literature that reports similar findings. Age and religiousness correlate with feelings of loneliness, although no significant relationships were reported between loneliness and sex, educational level, and marital status. The findings are important because they provide preliminary empirical evidence on levels of loneliness, while advance our understanding of loneliness among this population. Also they highlight the need to re-form social care policies since they fail to address loneliness among this ageing group. This is very concerning given the findings of this study that report loneliness as a common issue, and a daily reality, for this population.

The majority of the participants were found to subscribe to collectivistic cultural orientations. This oppose to previous findings that reported England as an individualistic country. The low sample size of this study did not allow examining cultural variations on self-stigma and loneliness among this population. However, the strong indications in the literature about their inter-relationships highlight the need for more research on the topic. Finally the findings of this study should be viewed with caution because of the small sample size of this study.

Chapter 9: Phase 2: Exploring mentally ill older adults' experiences of loneliness and self-stigma

The second phase involved a qualitative approach which aimed to explore how older adults with mental illness experience self-stigma and feelings of loneliness under the context of their cultural background. In this chapter, the qualitative approach is described and discussed. More specifically, the aims and objectives, research questions, the theoretical models influential to this study, and the study's design which is in line with the sequential mixed-methods design introduced in chapter 6 are discussed. The chapter also discusses and justifies the qualitative approach and methods utilised in this phase.

The chapter presents the eligibility criteria, sampling techniques and sample size of the main qualitative study. It continues with the discussion of the sampling size challenges, presents the interview schedule, and discusses the rationale of the selected research questions. The chapter also presents the objectives of the qualitative pilot study, discusses the lessons learnt from it, and draws upon its lessons to refine the initial interview schedule. The chapter then discusses the processes of data collection, the ethical considerations and presents the qualitative method of analysis.

9.1 Phase 2: Qualitative study

9.1.1 Aims and objectives

- To explore mentally ill older adults' experiences of self-stigma and feelings of loneliness within the context of their cultural values.

Objectives:

- To explore how older adults with mental health problems in nursing homes experience feelings of loneliness.
- To explore how older adults with mental illness in nursing homes experience self-stigma.
- To explore how cultural values are related to experiences of feelings of loneliness among older adults with mental illness in nursing home.
- To explore how cultural values are related to experiences of self-stigma among older adults with mental illness in nursing homes.

9.1.2 Research Question

- How do older adults with mental illness experience self-stigma and loneliness within the context of their cultural values?

9.1.3 Adopted theoretical models to self-stigma and loneliness

9.1.3.1 Socio-cognitive self-stigma model

The socio-cognitive self-stigma model developed by Corrigan and co-authors was adopted in this study. This socio-cognitive model gives self-stigma a socio-cultural dimension and strives to explain the process of self-stigma through socio-cognitive mechanisms. Bandura (1989) argues that socio-cognitive theory “favours a model of causation involving triadic reciprocal determinism. In this model of reciprocal causation, behaviour, cognition and other personal factors, and environmental influences all operate as interacting determinants that influence each other (p. 3)”. That is, people behave, act and make sense of the world around them through the intrinsic or extrinsic influences among cognition, behaviour, personal characteristics, and socio-cultural context. Expectations, beliefs and views in relation to people’s environments, and socio-cultural contexts determine the way they feel, act, and behave. This is significant in understanding the process of self-stigma. Corrigan and co-authors being influenced from, and being based on the socio-cognitive theory conceptualised the self-stigma model in an attempt to explain the process of self-stigma. According to them self-stigma is explained through three cultural constructed components: stereotypes, prejudice and discrimination. The socio-cognitive model is thoroughly discussed in chapter 2.

9.1.3.2 Interactionistic approach: Weiss model of loneliness

The interactionistic approach to loneliness was influential to this study. The interactionistic approach perceives loneliness as a multidimensional phenomenon, and attempts to conceptualise the concept of loneliness through two important components. That is, the deficiencies to people’s intimacy relationships/and the absence of an attachment figure, and the lack of an adequate social environment (Singh & Kiran, 2013; Tzouvara *et al.*, 2015). Weiss (1973), the main spokesman of the interactionistic approach, advanced the approach by suggesting two distinct types of loneliness, which is felt to relate to, and fit with older adults in nursing homes context: the emotional loneliness and social loneliness. Victor *et al.*, (2005) argued that Weiss’s typology of loneliness helped and advanced the loneliness ‘age-related’ literature. Weiss’s theoretical model is discussed in chapter 3.

9.2 Study design

The second phase of this study is in alignment with the sequential mixed-methods research design that was introduced in chapter 6 (section 6.2). The two phases were inter-related at the study's intermediate stage. This aimed at further explaining the quantitative findings due to the small quantitative sample size, and facilitating the implementation of the qualitative study, particularly on the sampling identification and the development of this phase's study design. As stated earlier the combination of mixed-method approaches are well-known across the health and social science research, including within the loneliness, self-stigma and individualism/collectivism (I/C) research fields. The complexity of the phenomena under investigation within these disciplines justifies the utilisation of a mixed-method approach as means of addressing this complexity. Both quantitative and qualitative research and a combination of the two methods have been implemented on exploring loneliness and self-stigma (e.g. Barg *et al.*, 2006; Griffiths, 2008; Drageset, 2011; Conner *et al.*, 2010; Livingston *et al.*, 2011; Cahill & Diaz-Ponce, 2011; Victor & Yang, 2012). This design also enabled the identification of eligible participants.

This phase utilised a phenomenological approach to address the second aim of this study (figure 12). That is, to explore the experiences of loneliness and self-stigma of older adults with mental health problems in nursing homes within the context of their cultural values.

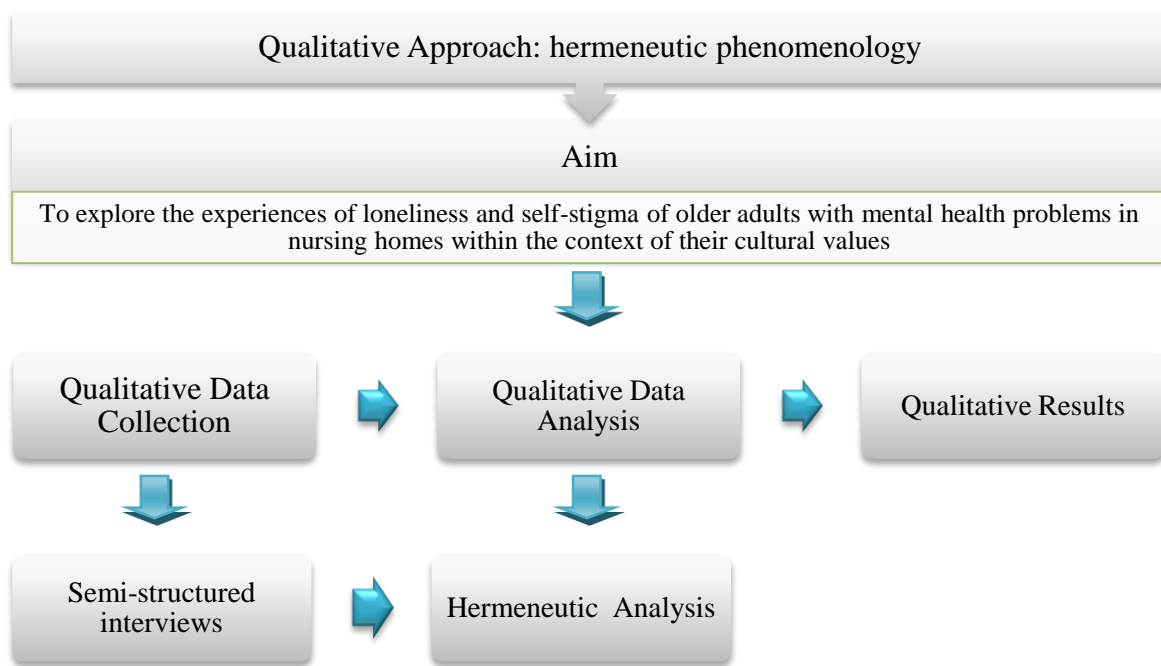


Figure 12: Phase 2: Sequential mixed-methods design

9.2.1 Qualitative approach: a hermeneutic phenomenological approach

Phenomenology is both a philosophical enquiry and a method of research (Finlay, 2008; Dowling & Cooney, 2012; Mayoh & Onwuegbuzie, 2013; Mayoh & Onwuegbuzie, 2015). Phenomenology as a philosophical enquiry, within its traditional philosophical context, advocates the exploration of people’s lived experiences. Specifically, “phenomenology as a philosophy is seen as a way of returning to and exploring the reality of life and living” (Tuohy *et al.*, 2013, p. 18). According to Valle *et al.*, (1989) the underpinnings of phenomenology lie in the propositions that world and lived experiences are inter-connected and cannot be perceived separately, because emphasis is given to the exploration of the world as lived by the person (seen in Lavery *et al.*, 2003). Husserl, who has been acknowledged as the father of phenomenology, introduced phenomenology as the movement of ‘doing philosophy’ (Tuohy *et al.*, 2013). However, phenomenology, attracted several followers and developed many different interpretations, since Husserl’s first conceptualisation.

Broadly speaking, two main and distinct types of phenomenology exist (although it should be highlighted that different sub-types lie within the two dominant phenomenological approaches): the ‘Husserlian descriptive phenomenology’, and the ‘Heideggerian

hermeneutic (interpretive) phenomenology’ (Finlay, 2008; Kafle, 2011). These types of phenomenology present core differences on the way research should be implemented. Descriptive phenomenology, which is influenced by Husserl’s work, describes the characteristics of a phenomenon rather than people’s lived experiences (Tuohy *et al.*, 2013). The main aim of descriptive phenomenology is to describe phenomena by putting aside the context of the phenomena and the researcher’s previous experience, knowledge, views and beliefs. The latter is achieved through “bracketing” which is a significant element of descriptive phenomenology. Hermeneutic (interpretive) phenomenology, on the other hand, which is rooted in *Heidegger*’s work, aims to explore people’s experiences as lived by them and not just to provide a description of phenomena. The main aspect of hermeneutic phenomenology is to interpret the meaning that people give to their experiences by also considering and recognising the role of the context of the phenomenon being studied (time, place, fore-structure) (Wojnar & Swanson, 2007; Kafle, 2011). Bracketing, in this form of phenomenology, has no place, since the researcher becomes one with the participant and the research; while the researcher’s previous knowledge and understanding help the interpretation of the findings (McComiell-Hemy *et al.*, 2009).

The concepts under investigation have been characterised as subjective and multi-dimensional. It is therefore, important to give voice to older adults to talk about their lived experiences, that is, their experiences of loneliness and self-stigma, in order to depict a more nuanced picture of the phenomena. As defined above hermeneutic phenomenology approach aims to explore and interpret the lived experiences of individuals. Thus this approach allows the researcher to deeply explore self-stigma and loneliness through older adults’ individual understandings of their experiences, and to expand the knowledge regarding the phenomena under-studied. The researcher, in this type of phenomenology, should not put aside his/her experiences and understandings, and remain objective, because it is through the researcher’s involvement in the research that interpretation occurs. For example, Berlin Harrlup *et al.*, (2009) utilised a hermeneutic phenomenological approach to study older women’s experiences of living with the risk of falls. The authors stated that through the hermeneutic phenomenological approach were able to ‘come close’ to the participants ‘life-world’ by exploring their daily lives, and identifying the way that the risk of falls was embedded in and was part of their world. Following this, the researcher in this study, through the utilisation of a hermeneutic phenomenological approach, was able to ‘meet’ older adults ‘life-world’,

explore their everyday lives, and identify how their experiences of self-stigma and loneliness were embedded in their world.

Self-stigma and loneliness has been characterised as two constructs tightly linked and influenced from peoples' cultural values. Rao *et al.*, (2007) states that diagnosis of mental illness is based and depends upon society's cultural values and norms, and that therefore stigma attached to the diagnosis is shaped by peoples' cultures. This notion is also reflected on the theoretical models of loneliness and self-stigma adopted in this study. The self-stigma model advocates that cultural and social constructs influence perceptions and beliefs about mental illness (through stereotypes), and thus influence the way people make sense and perceive their conditions (mental illness). In relation to loneliness Rokach and Neto (2005) propose that, loneliness is deeply related to peoples' social and cultural norms. Differentiations of cultural norms cause differentiations on the way people experience loneliness. Weiss' model of loneliness, which has been influential to the study, takes into account the social and cultural contexts of people in the form of social loneliness or/and emotional loneliness. Empirical research on self-stigma and loneliness literature also highlights the key role of societal and cultural contexts (see chapter 5). The cultural context of the mentally ill is, therefore, vital in understanding experiences of loneliness and self-stigma. According to Myers (2009) "qualitative research is designed to help researchers understand people, and the social and cultural contexts within which they live. Such studies allow the complexities and differences of worlds-under-study to be explored and represented" (cited in Thomas, 2010, p. 303). Therefore, a phenomenological hermeneutic approach was thought as the most adequate approach in providing a deep understanding of the experiences of loneliness and self-stigma within the context of older adults' cultural environments. Penner and McClement (2008) state that "a phenomenological analysis does not aim to explain or discover causes. Instead, its goal is to clarify the meanings of phenomena from lived experiences (p. 93)". Thus, this study applied a sequential mixed-method design, wherein a hermeneutic phenomenological approach was used during the qualitative phase, because it aimed to explore older adults lived experiences in relation to their cultural context, and not to identify causes and/or generate theories.

Mixed-method designs refer to the combination of both quantitative and qualitative methods, under the umbrella of an appropriate philosophical paradigm, which in this study's case is pragmatism. But how it is possible to mix phenomenology with other philosophical and

epistemological viewpoints, such as positivism? The philosophical underpinning of phenomenology in general, and hermeneutic phenomenology in particular, is, however, in line with a pragmatism philosophy and epistemology, that influences and governs this study. Herein, I will first provide an explanation on how phenomenology (both hermeneutic and descriptive), although a deeply rooted qualitative approach, and quantitative methodologies can offer areas for methodological and philosophical compatibility. Then I will explain how hermeneutic phenomenology approach can be used within mixed-method designs, by referring to examples from the literature.

Advocates of quantitative methodologies traditionally articulate propositions about research, reality, truth and knowledge that are governed from a positivistic philosophy. They believe that social observations should be treated as physical phenomena (Johnson & Onwuegbuzie, 2004), while absolute truth can never be found (Creswell, 2009a), although objective reality exists and can be measured (Creswell, 2009a). Objectivity is an essential component of this school of thought. Quantitative purists believe that the researcher should eliminate their own bias, and should retain his/her emotional distance from the object of the research (Johnson & Onwuegbuzie, 2004). For this school of thought subjectivity is incompatible with quantitative methodologies, and should be avoided. Phenomenology the way is conceptualised by Edmund Husserl (1859-1938), could be argued that presents philosophical similarities to the positivistic philosophy. That is not surprising, “...when one considers that the fore founders, Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976), were mathematicians with an appreciation for both object and subject... therefore...the scientific nature of the phenomenological method offers areas of methodological compatibility with more deductive approaches” (Moyah & Onwuegbuzie, 2015, p. 95). Gadamer (2004) argues that Husserl’s phenomenology emphasises objectivity while at the same time recognises and respects human’s subjectivity (cited in Moyah & Onwuegbuzie, 2013). Thus, the appreciation of both objects and subjects within phenomenological inquiry offers a ‘neutral area’ wherein phenomenology can be mixed with quantitative methods of research. One of the main objectives of Husserl’s descriptive phenomenology is to distance the researcher from the object of research by deliberately putting aside and disregarding all his/her past knowledge, beliefs and pre-assumptions regarding the phenomena under investigation (Chan, *et al.*, 2013; Moyah & Onwuegbuzie, 2015). Therefore the researcher should be emotionally detached and distant from the object of the study while should maintain his/her objectivity. This aligns with the positivistic philosophy, as outlined above, and constitutes one of the

main philosophical similarities between phenomenology and positivists philosophy, and thus quantitative methodologies. As Moyah and Onwuegbuzie, (2013) poignantly put it “these similarities (bracketing-objectivity) arguably provide a justification for combining descriptive phenomenology with quantitative methods concurrently because the axiological parallels would allow for a single research goal to be identified: the identification of the common features of an experience (p. 6)”.

This study’s qualitative approach is hermeneutic phenomenology. Hermeneutic phenomenology does not present philosophical similarities with positivism, as it is a qualitative approach tightly linked with and related to interpretivist/constructionist philosophy. The latter philosophy, however, aligns and fits into a pragmatist philosophy, and thus mixed-method approaches. Therefore hermeneutic phenomenology can also be adopted in mixed-method designs. Below I explain how the two approaches can offer areas for philosophical compatibility.

Qualitative purists emphasise multi-constructed and subjective realities (Sarantakos, 2013). They argue that truth cannot be measured nor can the ‘knower’ and the ‘known’ be separated to each other (Johnson & Onwuegbuzie, 2004). Advocates of qualitative research articulate assumptions that are in line with the interpretivist/constructionist philosophy. They think that people give meaning to the constructs around them through their engagement and interpretation of the world (Creswell, 2009b). Qualitative purists also prioritise the context and the subjectivity of people while disregard time and context free generalisations (Johnson & Onwuegbuzie, 2004). Hermeneutic phenomenology is consistent with the assumptions of an interpretivist/constructionist philosophy. One of the aims of hermeneutic phenomenology is to interpret the meanings that people give to their lived-experiences, by emphasising subjectivity and recognising the connection and closeness of the researcher with the research. Hermeneutic phenomenology, similar to interpretivist philosophy, advocates the existence of subjective realities, while views people as the centre of research, which cannot be articulated separately from the researcher. Thus, hermeneutic phenomenology can be utilised in a mixed-methods design which is under a pragmatism philosophical context. That is because pragmatism pertains to the combination of quantitative and qualitative methodologies since the aim is to thoroughly explore the subject under investigation and not to commit to any system of philosophy (Creswell, 2009b). Pragmatism gives equal weight to both quantitative and qualitative methods, and thus the philosophical underpinnings of each method

(positivism-constructivism). Thus, a hermeneutic phenomenology approach was utilised, since its philosophical underpinning aligns with the epistemological and philosophical stances of this study.

Hermeneutic phenomenology has previously been characterised suitable in use within sequential mixed method approaches. According to Moyah & Onwuegbuzie (2013; 2015), hermeneutic phenomenology strives to explore the lived experiences of people. They argue that prior to the implementation of a hermeneutic phenomenological approach, there is a need the researcher to identify what are these experiences. Therefore, the researcher should become oriented with the phenomenon under exploration. The process of the researcher's orientation within a phenomenon can be achieved through the implementation of a sequential explanatory mixed-method approach. I will go one step further to argue that since hermeneutic phenomenology (and phenomenology in general) aims to explore and interpret or describe (in the case of descriptive phenomenology) lived experiences, there is a need to identify people who actually experience the phenomenon so as interpret, share and talk about these experiences within a pragmatic experiential context. To put it simply we cannot explore peoples' lived experiences if we have not first identified people who have lived experiences of the phenomenon that a researcher wishes to explore. I therefore cannot deeply explore mentally ill older adults' experiences of loneliness and self-stigma if I have not been able first to identify those older adults who suffer from mental health problems and are potentially prone to feelings of loneliness and self-stigma. A sequential mixed-method design, therefore, which prioritises the implementation of the quantitative phase, provided an adequate means towards identifying of participants.

Mixed-method designs with a hermeneutic (or and descriptive) phenomenological approach in their qualitative phases are not uncommon in research (Dean *et al.*, 2011; Hamdan-Mansour *et al.*, 2011; Thornton *et al.*, 2011; Mayoh *et al.*, 2012). For example Dean *et al.* (2011), in a study of back-pain among rural workers used a mixed method approach with the first stage involving a questionnaire survey and the second phase involving an interpretative phenomenological analysis. They argued that the questionnaire survey advanced sampling identification and analytical understanding for the second phase; two advantages that this study also tapped into. In addition Thornton *et al.*, (2011) combined quantitative methods (self-reported assessment tool) with phenomenological inquiry drawing on interpretive phenomenological analysis in order to explore perceptions of Australian anti-smoking

campaigns among people who suffer from psychotic disorders. The authors stated that their methodological design provided the opportunity to identify participants for the phenomenological approach.

In summary a hermeneutic phenomenological approach was utilised in order for experiences of feelings of loneliness and self-stigma to be explored and facilitated within the context of participants' cultural values. A mixed-method hermeneutic phenomenological approach also advanced the identification of eligible participants, while provided rich and in-depth findings. Finally, phenomenological approaches are widely and effectively implemented in the loneliness (e.g. Evans, 2010; Hauge & Kirkevold, 2012; Kirkevold *et al.*, 2013) and stigma literature (e.g. Papadopoulos, 2009), while they are widely applied in ageing research (e.g. Heggstad *et al.*, 2013; Palacios-Ceña *et al.*, 2013; Palacios-Ceña *et al.*, 2014).

9.2.2 Data collection tool

For the aims of this study phase, a face-to-face semi-structured methodology was implemented. Interviews, in general, and semi-structured interviews, in particular, are the most common methods of data collection in qualitative research (Denzin & Lincoln, 2011). This method was applied because of its effectiveness to ascertain subjective experiences, perceptions, and views. Face-to face semi-structured interviews are well-employed within the loneliness (e.g. McInnis & White, 2001; Slettebø, 2008; Stanley *et al.*, 2010; Kvaal *et al.*, 2014) and self-stigma (e.g. Kranke *et al.*, 2011) literature. For example, Slettebø (2008) used semi-structured interviews, within the context of a hermeneutic phenomenological approach, in examining a sample of Norwegian older adults' experiences of living in a nursing home. While Stanley *et al.*, (2010) through semi-structured interviews, explored older adults and health providers' perceptions of loneliness in two Australian states. Semi-structured interviews are widely-used because they allow the researcher to formulate more questions on the participant's situation, and thus probe more information on the topic. Semi-structured interviews therefore aimed to the deep exploration of a phenomenon (Hersen, 2006).

As Denzin and Lincoln (2011) highlighted by using face-to-face semi-structured interviews during a research study, the researcher has the opportunity to approach individual's subjective realities such as personal experiences and attitudes which otherwise would remain inaccessible. Understanding that this study aimed to assess subjective experiences and beliefs upon two sensitive topics, that is, mental illness self-stigma and loneliness, face-to-face semi-

structured interviews were thought to provide an opportunity of building a relationship of trust and confidentiality with the participants. Therefore, the researcher probes deeper in the studied area of the participants' situation.

Face-to-face interviews were used also because of practical reasons. For example, the majority of older adults might not have access on computers and laptops, and therefore interviews through on-line resources such as skype could not be implemented. In addition, older adults who are residing in nursing homes might not have access on telephones and/or might not be able to stay on the telephone for a long time because they might suffer from various physical disabilities. Face-to-face interviews therefore were viewed as the most appropriate tool of data collection. Opdenakker (2006) argued that one of the main advantages of face-to-face interviews (comparing to other methods) is the *standardisation of the situation* that they can offer. The researcher has a better view on the situation of the participant, and therefore has more possibilities to create a good interview ambience. This is key for this study because the participants are of old age and discuss about sensitive topics such as mental illness stigma and loneliness. Therefore, face-to-face interviews help a relationship of trust to be built between the researcher and the researched. Participants therefore might feel more at easy to talk about their experiences in relation to these concepts, and provide deep and rich data which would not be remained unexplored through impersonal telephone interviews.

Face-to-face interviews are more time consuming than focus groups interviews (Oatey, 1999). However, one main disadvantage of focus groups is the possibility that one participant may dominate during the conversation and avert the other participants to express their experiences and perceptions (Oatey, 1999). In addition, participants' views may be influenced by the views of other members of the group so that the result will not reflect individual beliefs and opinions. Another practical issue with focus groups' is that some participants will not express their thoughts at all due to their embarrassment or fear of the presence of others.

To sum up, in this study face-to-face semi-structured interviews were used because they allowed the deep exploration of older adults' experiences of loneliness and self-stigma. Face-to-face interviews also allowed a relationship of trust to be built up between the researcher and the researched which was key aspect of this study. In addition, face-to-face interviews were used for practical issues that relate to this population's needs and characteristics. This

method also allowed the development of a good interview ambience which is important because of the sensitive nature of the concepts being examined in this study, and my willingness to minimise participants' stress and embarrassment, while at the same time to achieve deepness, and unaffected and sincere narrating of their experiences. Finally, face-to-face interviews have been widely used within the loneliness and self-stigma literature in approaching participants' subjective realities and inner perceptions, and thus justifies why a face-to-face interviews was used.

9.2.3 Eligibility criteria

Participants met the following eligibility criteria:

Inclusion Criteria

- Older adults ≥ 60 years old.
- Older adults who have been identified as experiencing mental ill health during the first phase (as assessed by interRai-LTCF tool during phase 1: DRS= ≥ 3 , AHS= ≥ 3 , ABS= ≥ 3)
- Older adults who possess the cognitive ability to participate in the study (as assessed by interRai-LTCF tool during phase 1: CPS= ≤ 3).
- Older adults residing in nursing homes in the county of Bedfordshire.
- Older adults who speak and understand the English language.
- Older adults who participated in the questionnaire survey (first phase).

Exclusion Criteria

- Older adults < 60 years old.
- Community dwelling older adults.
- Older adults who have not been identified as experiencing mental ill health (as assessed by interRai-LTCF tool during phase 1: DRS= < 3 , AHS= < 3 , ABS= < 3).
- Older adults who do not possess the cognitive abilities to participate (as assessed by interRai-LTCF tool during phase 1: CPS= > 3).
- Older adults who do not understand and speak the English language.
- Older adults who are not residing in nursing homes in the county of Bedfordshire.
- Older adults who did not participate in the questionnaire survey (first phase).

9.2.4 Sampling technique

Participants were purposively sampled through an “expression of interest” question provided at the end of the questionnaire survey. This sampling method was used because it provided flexibility to the researcher to sample participants from various personal and socio-economic-cultural backgrounds. Moreover non-randomised purposive sampling techniques are widely and broadly used in qualitative studies. The above method aligned with the aim of qualitative research, which was to explore and interpret a specific research question, and not to generalise the findings to the target population (Brocki & Wearden, 2006).

Participants who were willing to take part in the interviews process were asked to provide in a separate sheet their first initials, date of birth, and the name of the nursing home which were residing in. The researcher analysed the quantitative data and identified the participants who met the study’s eligibility criteria.

9.2.5 Sample size

Smith and Osborn (2008, p. 56) argue that “there is no right answer to the question of the sample size...”, and therefore, “Interpretive Phenomenological Approach distinct feature is its commitment to a detailed interpretative account of the cases included and many researchers are recognizing that this can only realistically be done on a very small sample – thus in simple terms one is sacrificing breadth for depth”. That is, in phenomenological approaches small sizes are preferable because they offer an in depth and extensive exploration of the subjects and phenomena under investigation.

The theoretical saturation technique was also used in order for the sample size of the qualitative study to be determined (Bryman, 2012). According to this technique during the qualitative data collection procedure the researcher analyses the initially collected data and produces understanding of the phenomena. Thereafter, the researcher continues the interviewing process by adding new units until meaningful information emerge. Once no new information emerges the qualitative data collection procedure comes to an end. Creswell et al. (2007) states the researchers should interview up to 10 participants in attaining saturation. However, the sample size of the second phase was determined to ≥ 10 participants. It is worth mentioning that due to sampling challenges in this phase (discussed section 9.2.5.1) saturation was achieved for loneliness, but not for self-stigma.

9.2.5.1 Sample size challenges

A significant challenge in relation to the sample size of this phase emerged. That is, participants who met the eligibility criteria of this study were deceased or moved out from the nursing homes, at the time of this phase's implementation. The researcher in order to maximise participation modified the second phase's criteria. Specifically, eligibility criterion "*older adults who expressed an interest to participate in the qualitative interviews*", and criterion *older adults who have been found to subscribe in individualistic and/or collectivistic cultural values through the quantitative phase*" were excluded (the initial criteria of this phase can be viewed in appendix 13). The former amendments were thought to be necessary in order theoretical saturation to be met. This strategy resulted in recruiting four more participants.

9.2.6 Development of the interview schedule

A protocol of the interview schedule (appendix 14), and potential probes were developed based on the adopted theoretical models of this study, as have been thoroughly described in chapters 2, 3, 4. For a full breakdown of the models used for the development of the interview schedule, please see figure 13.

9.2.6.1 Interview schedule questions

One of the main influential conceptual frameworks to this study was the individualism-collectivism (I/C) cross-cultural value paradigm (Triandis, 2001) which has been previously utilised in explaining various psychosocial phenomena. That is, people subscribing to different cultural values may interpret and experience psychosocial phenomena differently. The literature revealed (see chapter 4) that people from collectivistic countries give priority to their in-group interconnectedness and tight family bonds, their behaviour concur with their in-groups norms, values and views, and prefer to sacrifice their own personal achievements for the sake of their in-groups goals. On the other hand people from individualistic cultures are independent and more competitive, give priority to their personal goals over in-group goals, and their family bonds are characterised as 'weaker'. It has been also found that older adults valuing collectivistic cultures are more likely to live with their children, and their care to be solely provided by them, opposed to individualistic-oriented older adults who are more likely to be independent, and live alone with their care to be provided by public or private institutions. According to Chen and West (2008) there are five main components that people

differentiate in relation to cultural subscriptions; these are: *perceptions of self, goal relationships, significance of values, norms and attributes, and prioritising relationships* (Chen & West, 2008). One of the objectives of this phase was to explore older adults' cultural values based on the I/C cultural paradigm, and its five main differentiating components. This provided insights about differentiations in cultural values, and how these differentiations shape, influence and explain experiences of self-stigma and loneliness among this population. This is important given the amount of studies which indicated cultural variations in experiences of stigma and loneliness (see chapter 5). The questions that explored the I/C cultural subscriptions were:

- Could you please tell me a bit about your life before coming in the nursing home? (Explore self: *living arrangements, stay alone or with family members, never leave family environment, work environment*)
- Could you please tell me a bit about yourself ? (Explore self/priorities: *Family vs self, career vs family, successful at work, would you sacrifice your personal achievements for the sake of your family? Why? Why not?*)
- How close do you think families should be? (Explore family relationships: *How often should families see each other? How near should they live to each other?*)
- Can you talk to me a bit about your family? (Explore family relationships: *Tell me about the relationships you have had with your family? tight, close relationships with family? Get together often?*)
- In life what is important and worthwhile to you? (Explore personal values and norms: *for example family harmony, family should be united, family should stay together, children should take care of their parents when they get old, success, money, Why are these values important to you? What the most important values are for you?*)

The above questions explored cultural values, norms and beliefs of older adults. Specifically, the first set of questions provided an understanding of what priorities the interviewees gave, and how their living arrangements were formed before admitted to the nursing home. As discussed earlier peoples' priorities and living arrangements are key components that indicate cultural differentiations. The following set of questions aimed to explore interviewees' perceptions of family relationships. Also, they explored how the relationships between the interviewees and their families were. This explored how interviewees ideally think of family

relationships, and how their family relationships actually were. Family relationships and perceptions about family relationships are also two components that signify cultural differentiations within the I/C cultural paradigm. The last set of questions explored the values, norms, and beliefs of the interviewees. These questions aimed to explore what values mean to the interviewees, what their personal values were, what were the most important values for them, and why these values were important. By asking these questions I gained an understanding of how participants make sense of their cultural values, and whether they subscribe to specific cultural values or not. All the above questions derived from and aligned with the I/C cultural paradigm adopted in this study, and its differentiating components (*perceptions of self, goal relationships, significance of values, norms and attributes, and prioritising relationships*).

Corrigan and Watson (2002) developed the socio-cognitive self-stigma model. The model consists of three components that explain the process of self-stigmatisation: *stereotypes, prejudice and self-discrimination*. These components determine the process of self-stigma in the following way: 1) *stereotype awareness* that means that the people with mental illness are aware of the negative stereotypes towards them, 2) *stereotypes agreement* which means that people with mental illness agree with the negative stereotypes towards them, and 3) *self-concurrence* which means that people with mental illness apply these negative stereotypes towards themselves (see chapter 2). The socio-cognitive self-stigma model by Corrigan and co-authors influenced the development of this study's interview schedule (in relation to self-stigma). The second objective of this study was to explore how older adults experience self-stigma. I explored the latter by posing questions about their perceptions of mental illness, how they think others think of older adults with mental illness, and finally if they endorse others' perceptions about mental illness, and apply to themselves. Questions that explore the former include:

- What does poor mental health mean to you? (Explore their understanding of the condition: *could you give me some examples?*)
- What do others think about older adults who have poor mental health? (Explore if they are aware of the stereotypes towards mental illness: *do you think that others view older adults who have often sad mood and behaviour differently? If yes, how? Do they view them negatively/positively? Why do you say that?*)

- How do you personally view older adults with poor mental health? (Explore stereotype agreement: *do you view them differently, unworthy, inferior? If yes, how? What kind of thoughts do you have when you think about older adults with poor mental health?*)
- Do you think that you have sometimes poor mental health? (*If yes, how do you experience it? How would you describe your experience?*)(*If no, what makes you feel happy?*)
- How does that make you feel about yourself? (Explore stereotype application: *Does this make you feel bad, sad, unworthy, isolated, burden to your family? Why do you feel that way? Do you talk to others about it (having poor mental health), If yes, how do you describe yourself? If no, Why?*)

The above set of questions explored interviewees' experiences of self-stigma. This was achieved through the exploration of stereotypes awareness, endorsement, and application. One question about mental illness opened the discussion. The main reason for posing this specific question was to explore how older adults understand and make sense of mental illness. The questions about stereotypes awareness of mental illness self-stigma then followed. By doing so, I had the opportunity to explore if older adults are aware of the negative stereotypes that the public holds, and attaches towards mental illness. This was an important component of the process of self-stigma, and thus experiences of self-stigma, since stereotypes and misconceptions about mental illness have been found to influence peoples' perceptions about the condition. The discussion continued with questions about stereotypes endorsement and application. The two former components also explained self-stigma, and have been found to significantly affect people's views about mental illness. The exploration of stereotypes endorsement and application provided an understanding on whether or not older adults experience self-stigma and more importantly how they experience it. No direct questions about experiences of self-stigma were posed because of the sensitivity of the concept being studied (mental illness self-stigma), and my willingness not to cause any extra stress and discomfort to the interviewees

The interactionist theory of loneliness was influential to the qualitative phase of this study. Weiss, who is one of the main advocates of the interactionist theory, proposed two distinct types of loneliness: *the emotional loneliness* and the *social loneliness* which have advanced the loneliness 'old-age' research (Victor *et al.*, 2005). According to Weiss (1973) emotional

loneliness results from the lack of emotional connections that are caused by deficiencies of intimate relationships. Loss of a loved one, divorce, and absence of friends are only some of a number of facets which form this type of condition. On the other hand, social loneliness results from the lack of social relations. Relocating, being excluded from community organisations, and not belonging to groups are some examples of this type of loneliness. The characteristics that Weiss attributed to loneliness seem to relate to older adults in nursing homes. For example, older adults in nursing homes might experience emotional loneliness since they are away from loved ones, and might experience social loneliness since they have been relocated to new environments. The use of Weiss theoretical distinction of loneliness in this second phase of this study, provided useful insights into the experiences of loneliness among this population, while allowed the in depth exploration of the phenomenon. The two themes that will be explored are *emotional loneliness* and *social loneliness*. The discussion points regarding the concept of loneliness has been formed by a) the Weiss's distinction of loneliness, and b) the literature review of this study. The questions involved:

- How would you describe your life in this nursing home? (Explore feelings about his life in the nursing home: *boring/routine, easy going/strictness, much to do, quality, safety, therapy*).
- How did you feel when you first moved here? (Explore feelings about his experience of relocation: *do you still feel this way today/now? How do you feel about being away from your previous environment? Why do you feel this way?*).
- Do you often take part in any activities taking place in the nursing home? (Explore social engagement: *If yes, do you enjoy them? What activities do you do here? If no, why?*).
- How are your relationships with the other residents here like? (Explore emotional loneliness: *close, good, feel attached to someone*).
- Do you have someone here that you could talk about very personal things with? (Explore emotional loneliness: *if yes how you would describe your relationship with him/her? If no, would you like to be able to talk with somebody about personal things? If yes why? If no why not?*).
- Do you have family or friends that visit you (*if yes how often? How does it make you feel?*)

- Do you sometimes feel lonely here? (*if yes when do you feel lonely and why? if not Why do you think that is?*)

The above questions were asked in order for the experiences of loneliness among older adults to be explored. The questions referred both to the emotional and social loneliness which are two main components that explain loneliness among older adults. The questions regarding emotional loneliness asked about family, friends, relationships in the nursing home, and attachment figures, while the questions about social loneliness asked about social engagement, social activities, and relocation. All the above allowed for the exploration of the third objective of this phase which was to examine the experiences of loneliness among older adults in nursing homes.

The interview schedule closed with one question with neutral context, so that participants had time to unstressed themselves as well as to share their thoughts, and make any suggestions. The questions included in the interview schedule were pilot tested, and amendments were made where it was necessary. The pilot study, as well as the lessons learnt from it in relation to the interview schedule, is next discussed.

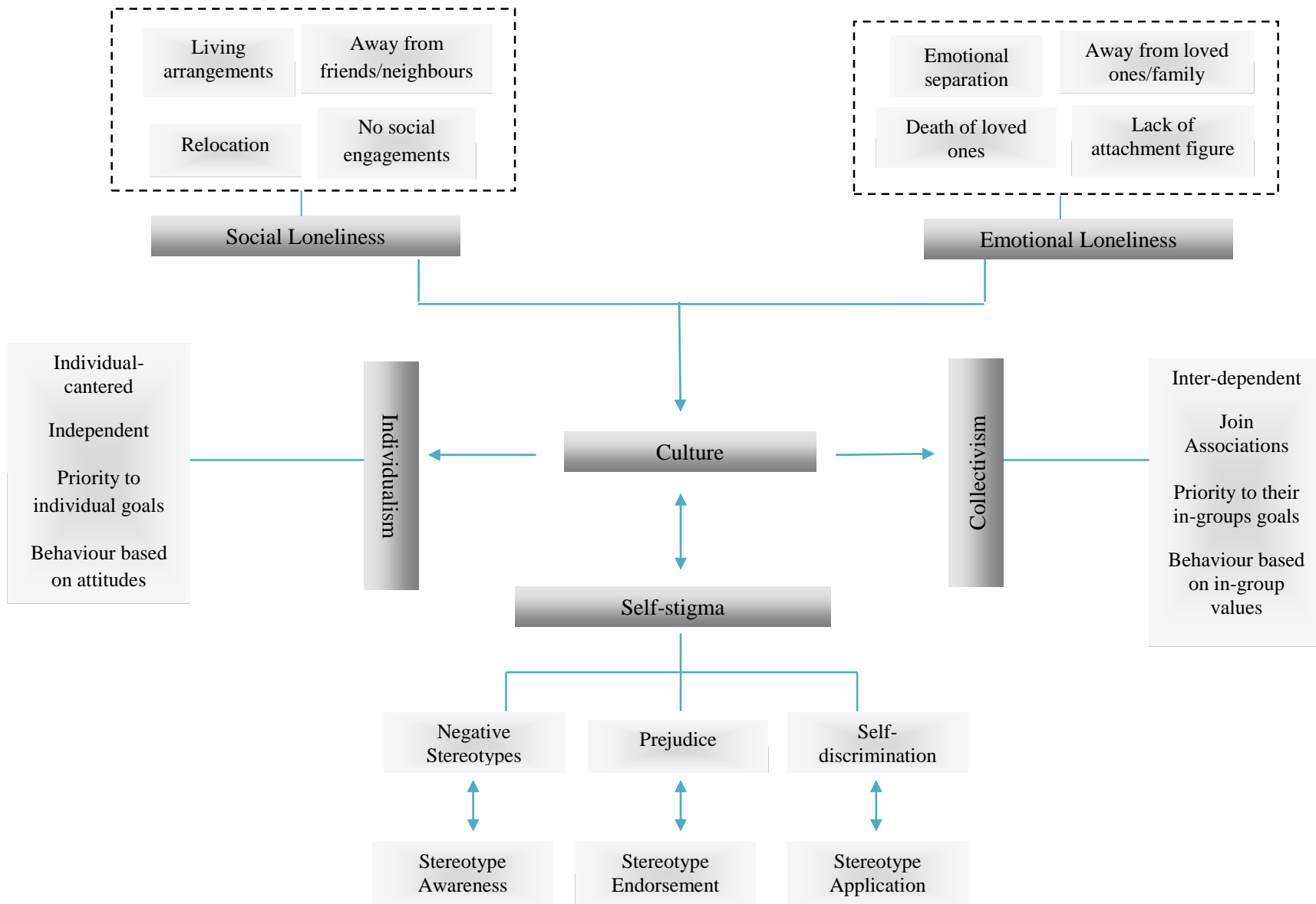


Figure 13: The theoretical underpinning of the interview schedule

9.2.7 The qualitative pilot study

Pilot studies are important because of the valuable information that they provide. Pilot studies are often used to pre-test the feasibility of a research project, its research design, recruitment procedures, research instruments, and response rates. By doing so, the researcher is in a better position to identify, and amend any faulty components. As stated in section 7.6, both phases of this study were pilot tested. The objectives of the qualitative pilot study, and the lessons learnt from it, is herein discussed and presented.

9.2.7.1 Objectives of the pilot study

The objectives of the qualitative pilot study concerned:

- a) The recruitment procedures of older adults.
- b) The administrative procedures of the interviews.
- c) The organisation of the interviews (e.g. place, time).
- d) Problems with understanding certain questions included in the interview schedule.
- e) The sensitivity of the questions included in the interview schedule.
- f) The duration of the interviews.
- g) The effectiveness of the interview schedule.

9.2.7.2 Sampling technique and sampling size of the pilot study

The qualitative pilot study served more practical and technical purposes. Therefore, 3 participants were purposively selected for the needs of the pilot study. The participants were identified through the 'expression of interest list' during the quantitative pilot study. The nurses approached the participants and asked if they were still willing to take part in the interviews. An information sheet and an informed consent form were given to the participants prior to the interview. All three participants agreed to be interviewed. Participants were assured that the interviews were anonymous, no names were collected, while pseudonyms were used, and voluntary. That is, the participants had the right to withdraw at any given time without providing any reason why. For an overview of the interview schedule, participant information sheet, and consent form used during the qualitative pilot study please see appendixes 14, 15, 16 respectively. Ethical approval for the pilot study was obtained by the Institute for Health Research Ethics Committee (appendix 17).

Similar to the quantitative pilot results, the findings of the qualitative pilot study were embedded in the analysis of the findings of the main qualitative study, and therefore were not separately presented. However, the lessons learnt from the qualitative pilot study are below discussed.

9.2.7.3 Lessons learnt from the pilot study

This qualitative pilot study aimed to test points a-g, as they reported in section 9.2.7.1. The pilot study, as stated earlier, received clearance by the Institute for Health Research Ethics Committee. The valuable lessons learnt from it are below presented and discussed.

The recruitment process of the nursing homes during the pilot study was based on the study's first phase (quantitative pilot study). The nursing home manager who agreed to participate in the questionnaire survey pilot study was re-approached during the qualitative pilot phase. The manager was informed in advance about this study's two phases. Therefore the manager was willing to provide access to the researcher during the second phase (qualitative pilot study). The qualitative pilot study's recruitment process of the participants was based on an "an expression of interest question" at the end of the questionnaire pilot survey. That is, participants who participated in the quantitative pilot survey were asked whether they wished to take part in the interviews. Participants who expressed an interest to the interviews wrote their first initials, dates of birth, and name of nursing home down in a separate sheet, and were approached during the qualitative pilot study. Three participants were re-approached for the qualitative pilot study. Similar to the quantitative pilot study's recruitment process the nurses helped the researcher to recruit the participants. That is, the nurses initially approached the participants and asked them whether they wish to talk to the researcher or not. In almost all cases (2 participants out of the 3 initially approached) participants recognised the researcher, while all of participants appeared to be happy to discuss with her. The participants were friendly and comfortable since they already knew the researcher. The recruitment process of the participants during the qualitative pilot study was effective. The researcher approached the participants who were willing to participate in the interview, and they have already been informed of and agreed to do so. Participants went under no stress since they were already aware of the researcher's visits in the nursing home. The former method of recruitment was also advantageous because of the existing familiarity and previous relationship with the participants. The participants had previously been informed about the nature and scope of the study, and therefore it was easier for them to decide whether to

participate or not. The participants appeared to be happy about the researcher's visit in the nursing home. For example, before and during the interview one participant expressed her gratitude about the researcher's visit, while she was pleased that she had someone to talk to. In other case the manager informed the researcher that the participant was waiting for her arrival all day, and he was constantly asking the manager whether and when the researcher was going to be there. Overall, the recruitment process of the qualitative phase was smooth, precise, efficient, and is followed during the main qualitative phase.

The response rate during the qualitative phase was high. As stated earlier the nursing home manager had already agreed to provide access to the researcher. One nursing home was approached, and the manager was happy with the researcher's going back to continue her recruitment. Older adults were also willing and happy to talk to the researcher. Three older adults were approached, and all of them agreed upon participation in the qualitative pilot study. The researcher had already built up a relationship of trust with the participants, which had a significant good impact on the pilot's recruitment process, and thus the pilot's response rates. The participants were already informed about the implementation of the pilot study by the researcher. The previous personal relationship between the researcher, the participants, and the nursing home managers was one key factor that explains the high participation during the pilot study.

Although the interviews did not involve any administration procedures, it is sufficient to assess and discuss the process of the interview during the pilot study. The interviews took place in the nursing home. The researcher asked the manager to provide her with a room in which the interviews could be held. The manager was willing to help, but the room that was provided, was isolated from the main facilities of the nursing home. Two of the participants were able to walk through the main facilities of the nursing home to reach the interview room. However, one of the participants had no walking abilities. Therefore the participant had to use his wheel-chair. The participant was of old age, and unable to move his wheel chair all the way down to the interview room by himself. The manager was willing to bring the participant to the interview room. After the interview there were no staff members around to help the participant to return to the main facilities. The researcher tried to make the participant to feel comfortable, and asked him if she could help him to go back to the main facilities. Once the participant agreed, the researcher helped him. It is important to consider all the above when research is taking place in care home settings.

The pilot study interviews lasted approximately 45 minutes. Only the first interview lasted more than an hour, but this was partly because of the researcher had no previous experience with qualitative interviews. The researcher did not strictly follow the interview schedule, and she overall had no control over the interview. That is, the interviewee was driven the interview, and was talking about anything she wished of. The participant preferred talking about things important to her and not directly relevant to the study's objectives. The researcher also repeated some of the questions and in some cases she formed new questions that were not included in the interview schedule. The latter is strongly related to the researcher's inexperience, and unfamiliarity to qualitative techniques. In order to overcome the former the researcher assessed the interview and its outcome. The researcher discussed all the above with her supervisors. By doing so the researcher identified the areas which needed improvement, and realised the importance of the development and application of techniques during the main qualitative study's interviews. After reflecting upon the first interview the researcher interviewed two more participants. The other two interviews lasted approximately 45 minutes each. The interviews were more effective while the researcher had control over the interview process. Once the participants were talking about something irrelevant to the study's aims, the researcher were kindly asking them to proceed on with the interview. After the interview the researcher spent some time with each of the participants and they talked about what the participants wished of.

Participants did not seem to have any particular problem understanding certain questions during the pilot study. However the participants seemed to prefer to use the term 'mental illness' when they were referring to mental health problems either to themselves or to other residents with mental health problems. Overall, the pilot study's participants seemed to be familiar with the term. Participants of the qualitative pilot study had insight into their illness, and maybe this could partially explain why they preferred to use the term 'mental illness'. Participants who have no insight into their illness they might prefer to use the term 'poor mental health'. However one participant who had no insight into his condition when he was asked to state his opinion about 'poor mental health', he replied that he had never heard this phrase again and he asked for clarifications. The researcher replaced the term 'poor mental health' with the term 'mental illness' during the pilot study's interviews. According to the lessons learnt from the pilot study, the term 'poor mental health' was replaced by the term 'mental illness' during the interviews of the main qualitative study, while the term 'poor

mental health' acted as a probe phrase. At the end of the qualitative pilot study's interviews the researcher asked the participants to provide their feedback about the length, the process of the interviews, and the sensitivity of the questions. All participants stated that the interviews were not long, that the process was good enough, and although some of the questions could be characterised as 'sensitive', they did not feel stressed and/or uncomfortable. The participants also stated that the interviewer's approach towards them was very good. Overall, the questions included in the qualitative pilot study's interview schedule were effective. That is, the questions gave the opportunity to the interviewee to share his/her opinions about the subjects under exploration. The researcher, however, rephrased one question that explores cultural subscriptions in the qualitative main study's interview schedule. The main reason was that the question did not effectively document participants' personality traits. Personality traits often depict peoples' cultural identifications, and thus they are a key component of culture. The question was phrased "*Could you please tell me a bit about yourself now?*" and it was re-phrased to "*How would you describe yourself/personality?*" By doing so, the researcher better understood participants' personality traits, and thus their cultural environment. Finally, the phrase 'people in the community' was included in the main qualitative study's interview schedule. The phrase refers to the general public's perception, and views towards mental illness. The main reason is to avoid confusion and remain specific.

Overall, the qualitative pilot study was precise, and effective. The questions included in the qualitative pilot study interview schedule were not extremely sensitive, and therefore they gave no extra stress to the participants. Although the researcher lacked interview techniques, the interview had the best possible outcome. Participants were happy with the researcher's approach, time and administrative processes of the interviews. The interview schedule of the pilot study was overall effective, but minor changes were required to maximise opportunities of insight into the participant's experiences. The amended interview schedule based on the lessons learnt from the qualitative pilot study was used during the main qualitative study, and can be viewed in appendix 18.

9.3 Recruitment procedures during Phase 2

The recruitment process of the main qualitative study (Phase 2) was as follows: The researcher having the list of all the participants participated in the main quantitative study (Phase 1) re-approached the nursing homes which had already provided access to the

researcher, and therefore agreed on participation. The researcher initially called the nursing home managers to arrange a convenient time and date. Once a convenient time was arranged, the researcher re-visited the nursing homes.

The list with the eligible participants was given to the nurses. The nurses helped the researcher to identify those participants who were willing to take part in the interviews. The researcher gave key information about the participants to the nurses. The key information involved participants' first initials and date of birth. The nurses then identified the eligible participants. Participants, who did not express an interest to participate in the interviews (but were also approached and asked to be interviewed in order to maximise recruitment), were identified through key personal information provided on the questionnaire tools, that is, date of birth, age, gender, and time of residence in the nursing home. The information was then cross-checked with the LTCF assessments, so that any mistakes can be avoided. Once eligible participants were identified by the researcher (with the help of the nurses please see above) they were initially approached by the nurses. The nurses asked the eligible participants for their permission for the researcher to talk to them. This recruitment approach minimised possibilities of stress. Participants who agreed to talk to the researcher were then approached. It is worth mentioning, however, that the researcher had already developed a close relationship with the participants through the main quantitative phase of this study. That was helpful since older adults went under no stress when the researcher approached them in order to schedule a convenient time to conduct the interview.

Overall, participants remembered the researcher from her last visit in the nursing home for the purposes of the quantitative main study. Only in one case did the researcher have to introduce herself, and talk about her role in the University. All but one interview took place the same day. The interviews were held in a quiet room in the nursing homes. Participants who were physically disabled (5 participants) or did not wish to leave their rooms (1 participant) were interviewed in their rooms.

The researcher reminded the participants about the study and explained them the process of the interview. The researcher then read the participant information sheet out loudly to the participants (appendix 15). The researcher re-assured that the study was anonymous (pseudonyms would be used), and voluntary. She then explained how data confidentiality would be assured and asked participants if they had any questions and/or concerns in relation

to the information which was provided to them via the participant information sheet. The researcher then administrated the consent form (appendix 16). In the same line the researcher read out loudly the consent form to the participants. Then the researcher asked the participants if they had comprehended the information provided to them via the consent form. Participants were then asked to provide their written informed consent. Participants who were unable to provide written consent (because they were physically disabled to do so) provided an oral consent instead.

All the interviews were audio-recorded and were transcribed by the researcher. The audio-recordings were destroyed when transcription was over.

9.4 Ethical considerations

Anonymity of the participants and confidentiality of the data are two of the main considerations of this study. The participant information sheet (appendix 15) and informed consent form (appendix 16) were distributed to the participants prior to the interviews. The participant information sheet contained information regarding the research study. Specifically the aim of the study, the procedures of the study and the reason why participants have been selected were outlined in the participant information sheet. The participants were also informed through the participant information sheet about what will happen with the results of the study, and how their participation would be kept confidential. Mental illness self-stigma and loneliness are very sensitive conditions; as such, the researcher tried to ensure that participants would not endure any kind of stress. Participants were therefore given breaks when it was necessary, while they were informed that the study was voluntary and they could withdraw at any time without stating the reason why. All the contact details (researcher and supervisors) were included in the participant information sheet for clarifications to any questions. No names were collected and pseudonymous were used. Once participants had understood the information included in the participant information sheet, written informed consent was sought through the consent form. The consent form asked participant to voluntary agree: a) that they fully understand what the research study is about, b) that they understand that participation is voluntary and that they can withdraw at any time, c) that they understand that the data collected will be treated with confidentiality, and that d) this study has ethical clearance. In any case that the participants were willing to be interviewed but were unable for any reason to provide written informed consent, oral informed consent was accepted.

To further increase likelihood of anonymity in this study, the interviews were anonymous and pseudonymous were used. Furthermore unique identifiers were allocated when direct quotes were used to maximise participants' confidentiality. This helped reduce the possibility of any collected information being traced back to the participant.

The interviews were audio-recorded. The audio recordings were destroyed, and all transcriptions were stored and secured in the researcher's office. Specifically the transcriptions were stored in a locked cabinet in the researcher's office, and only the researcher has access on the cabinet's key. Electronic data were saved in a password protected laptop. The laptop from the Institute for Health research requires an ID and password in order access to be gained. The password and ID are unique for every each research staff and research project, and without knowing them access in the computers cannot be obtained. The files are also protected by a unique password that only my supervisors and I had access to. Finally all data were encrypted using the University's of Bedfordshire software. All computers and laptops are protected by security software such as anti-virus programs which are regularly updated. The data are also securely backed up to ensure that the data is never lost. Finally, participants who would decide to withdraw from the study were assured that the data collected at the point of their withdrawal would be destroyed, and would not be included in this study's findings. The interviews were audio-recorded, and this was made clear to the participants before informed consent was obtained.

Ethical approval for the main qualitative study (Phase 2) was obtained by the Institute for Health Research Ethics Committee, University of Bedfordshire (appendix 19).

9.5 Qualitative data analysis

A range of analytic procedures can be employed in qualitative research studies. Each of them seems to focus on particular types of data and adheres to particular methodological models (Sarantakos, 2013). The qualitative approach of this study (hermeneutic phenomenology) triggered the utilisation and implementation of a qualitative hermeneutic analysis of the qualitative data as this has been suggested by Hauge and Kirkevelond (2012) To simplify the steps which were followed during the analysis, the researcher structured them in four stages:

- Stage 1: awareness of the text
- Stage 2: themes identified

- Stage 3: re-reading transcripts
- Stage 4: exploring variations (Hauge & Kirkevelond, 2012)

The above stages were followed during the analysis process of the data. More specifically, all the interviews were listened several times, and were transcribed with accuracy. After the accurate transcription of the recordings, the researcher read the transcripts again to familiarise herself with their context. By doing so, the researcher gained an initial understanding about participants' experiences of loneliness and self-stigma, and how these experiences interrelate with their cultural contexts. After the researcher became quite familiar with the transcripts, and was quite confident with their context, she started identifying nodes and themes by examining the transcripts in more detail. Three main themes were identified: loneliness, stigma, and culture. Through this second step the researcher comprehended how older adults describe their experiences. Then identified main themes for each initial theme of each concept under investigation was identified (e.g. initial theme loneliness: main theme: social loneliness). After the main themes were identified the researcher re-read the transcripts in order to gain a new understanding. Through this process sub-themes were generated. For example, for the concept of loneliness, one large theme was emerged e.g. social loneliness, then, three main sub-themes were identified e.g. social engagement. The third step involved the re-reading of the transcripts, in order to obtain a new understanding. That is, to seek any differences between participants' experiences of loneliness, and self-stigmatisation within their cultural context. The researcher also cross-checked the initial themes, identified any differences between participants, and identified new themes and sub-themes where it felt necessary for the better interpretation of the findings. The fourth and last step involved the overall interpretation of the findings. Here the researcher merged all the data and sought explanations on whether and how older adults with mental health problems experience loneliness and self-stigma, and how their cultural subscriptions implicitly or explicitly relate to experiences of loneliness and self-stigma.

Qualitative hermeneutic analysis as has been suggested by Hauge and Kirkevelond (2012) and utilised in this study aligns with the qualitative methods, approaches and philosophical underpinnings of this study. This justifies the utilisation of this method of qualitative analysis. Also as the researcher is novice in qualitative research she felt that the method provided her with a sense of analytical freedom as there is no absolute structured one-to-one

steps. As Max van Manen (1990) states “the method of phenomenology and hermeneutics is that there is no method (p. 30)”. That is, there is no one step-by-step method to be followed when someone applies hermeneutic phenomenological approaches. This allows researchers to have a freedom during the analysis of the data by mainly aiming to the accurate and thorough interpretation of the data, and thus the lived experiences of participants.

The analysis of the data was performed using the software package for qualitative data QSR NVivo10.

9.5.1 Trustworthiness and credibility

Trustworthiness is a key aspect of qualitative research. A number of criteria need to be met so that trustworthiness to be achieved. In this study, Guba's criteria of trustworthiness, as they have been reviewed and outlined by Shenton (2004), were highly influential. Specifically, credibility (which is equivalent to external validity in quantitative research) was sought through “prolonged engagement” (Shenton, 2004, p. 65). That is, the development of an early familiarity with the participants, their environment (nursing homes) and the researcher. Guba argues that early engagement is advantageous for both the researcher and the participants. An early engagement results to an adequate understanding of what it is expected from the implementation of the study, and to the establishment of relationships of trust between the parties. In this study prolonged engagement with participants' environment was achieved through the main quantitative study (Phase 1). Relationships of trust between the researcher, the participants, and their environment (nursing homes) were established prior to the implementation of the main qualitative study (Phase 2). The relationship of trust between all the parties (researcher/participants, and researcher/managers of nursing homes) advanced not only the credibility of the qualitative findings, and the overall qualitative arm of the study, but its overall implementation.

Finally in eliminating bias and personal preferences during the implementation of the study and its analytical process (so that to improve credibility) the researcher used the method of ‘debriefing’. Linckon and Guba (1985) and Shenton (2004) argue that frequent debriefing sessions help researchers to recognise their own biases by exploring different aspects of the phenomenon being studied, that otherwise would remain under-explored. The former method is not uncommon in research. Hsieh's (2007) study is one such example, among others. In her study about the views and perspectives on learning and teaching in the native language

among 10 Taiwanese native language teachers, she used the technique of debriefing. She argued that through the former technique she improved credibility by probing “biases, meanings and bases for interpretation” (p.92). The debriefing sessions was held among the researcher and her supervisory team. Through the meetings the research gained a new understanding of the study, while she was helped in revealing her own biases, probing meanings, refining themes, and illustrating interpretations. For example, the researcher during the analysis of the qualitative findings identified a number of initial themes and sub-themes in relation to the concepts under examination. With the method of debriefing the researcher was helped to identify her own biases, eliminate them, re-think emerged themes, and adjust where it was necessary for the best interpretation of the findings. One such example is the sub-theme ‘distance’ in relation to social loneliness. The initial sub-theme was ‘relocation’. However, in the debriefing sessions it was revealed that the researcher was biased from the literature and the theoretical model of the concept of loneliness adopted in the study. After constructive discussions the sub-theme was re-phrased to ‘distance’. Here the sub-theme indicates not only the psychical distance that participants’ endure because of their relocation from their previous environments, but also the emotional distance that such a condition may entail.

9.6 Summary

The mixed-methods design of the second phase of this study involved a hermeneutic phenomenological approach which aimed to explore older adults’ experiences of loneliness and self-stigma under the context of their cultural backgrounds. A hermeneutic phenomenological approach aligns with this study’s philosophical and epistemological underpinnings, and with the self-stigma and loneliness models. Semi-structured interviews were used in order the concepts to be adequately explored.

A non-randomised purposively sampling technique was used. The sample size of the study was determined using theoretical saturation. One key challenge concerns the sample size of the study, and therefore saturation. In maximising the sample size the researcher refined the initial eligibility criteria. This method increased the sample size of this phase, and allowed saturation to be achieved. Yet saturation was achieved in relation to loneliness, and not self-stigma.

The interview schedule involved research questions in relation to loneliness, self-stigma, and culture. The questions were derived from and based on the theoretical models and the

literature review of this study. A qualitative pilot study was implemented so that technical and practical issues to be addressed prior to the implementation of the main qualitative study. The pilot study provided valuable lessons learnt, and particularly in relation to the interview schedule. The researcher made minor amendments in the initial interview schedule to better address this phase's objectives.

Participants' anonymity and data confidentiality was assured during the implementation of this phase. Information sheet and consent form were distributed to the participants. Participants were assured that the study is voluntary, while pseudonyms were used. The interviews were audio-recorded. Incomplete data were not included in the analysis, while digital data were destroyed after transcription. The analysis of the data was performed using the software package Nvivo10. A hermeneutic phenomenological analysis was used, and involved four broad steps. That is, aware of the text, themes identified, re-reading of the transcripts, and overall interpretation. This method of qualitative analysis aligned with the hermeneutic phenomenological approach of this study.

Chapter 10 Phase 2: Qualitative Findings

This chapter presents the findings from the semi-structured interviews with older adults experiencing mental health problems and residing in nursing homes. Specifically section 10.3 and 10.4 present the themes and sub-themes exploring the experiences of loneliness and self-stigma among this population. Section 10.5 presents the themes and sub-themes exploring older adults' cultural context.

The chapter also discusses the findings in relation to previous literature, and finally discusses a new theoretical model that explains loneliness and self-stigma among this population.

10.1 Results of participants recruitment

All participants (n=16) who participated in the quantitative main phase were eligible to take part in the interviews. From those, 12 had expressed an interest to participate in the qualitative main study (Phase 2). However, 2 of them were deceased, 1 moved to another nursing home, 1 was cognitively worse, and 2 did not wish to take part. Therefore, the initial recruitment process (through an expression of interest) during the main qualitative study resulted in the recruitment of 6 participants. As stated in section 9.2.4, participants who had not expressed an interest to be interviewed were also approached and invited to take part in the interviews in order to maximise participation. This resulted in the recruitment of 4 more participants. Therefore a total of 10 older adults participated in the main qualitative study (Phase 2).

10.2 Socio-demographic findings

The findings presented below describe participants' socio-demographic characteristics. The age range of participants was 60–92 years. Five participants were male, while another 5 were female. Two participants were married. The rest of the participants were widowed (n=4), single (n=3), and divorced (n=1). Participants were recruited from the nursing homes participated in the main quantitative study (Phase 1) (n=6). The names of the participants stated below are pseudonyms. Table 10 presents participants' socio-demographic details.

Table 13: Participants socio-demographic characteristics

<i>Hope</i> , is between the ages of 60 to 70, British, and single. She has insight into her mental illness.	<i>Janet</i> , is between the ages of 60 to 70, British, and married. She has insight into her mental illness.
<i>George</i> , is between the ages of 60 to 70, British, and single. He has insight into his mental illness.	<i>Ian</i> , is between the ages of 91 to 100, British, and widowed. He has no insight into his mental illness
<i>Kieran</i> , is between the ages of 60 to 70, British, and single. He has no insight into his mental illness.	<i>Janis</i> , is between the ages of 81 to 90, British and divorced. She has no insight into her mental illness.
<i>Rose</i> , is between the ages of 71 to 80, British, and widowed. She has no insight into her mental illness	<i>Silvia</i> , is between the ages of 60 to 70, British and widowed. She has no insight into her mental illness
<i>John</i> , is between the ages of 71 to 80, British, and married. He has no insight into his mental illness.	<i>David</i> , is between the ages of 81 to 90, British, and widowed. He has no insight into his mental illness.

10.3 Experiences of loneliness among mentally ill older adults in nursing homes

The analysis revealed four main themes regarding older adults' experiences of loneliness which align with Weiss's model of loneliness and the literature review of this study. The themes were further analysed into sub-themes. The four main themes involved: social loneliness, emotional loneliness, emotional reactions, coping with loneliness. These main themes were then categorised into sub-themes to further describe the experiences of loneliness among this sample. The themes and sub-themes are below presented.

10.3.1 Social loneliness

According to the theoretical model of this study social loneliness is one key component of explaining experiences of loneliness. Social loneliness refers to the absence of an inadequate social environment which results to inadequate social relations and unmet social integration. These unfulfilled needs intensify experiences of loneliness (for an overview please see chapter 3). The analysis revealed three sub-themes that describe participants' experiences of social loneliness. These were: social environment, social engagement, and distance (figure 14). The sub-themes describe experiences of loneliness in relation to participants' social relationships.

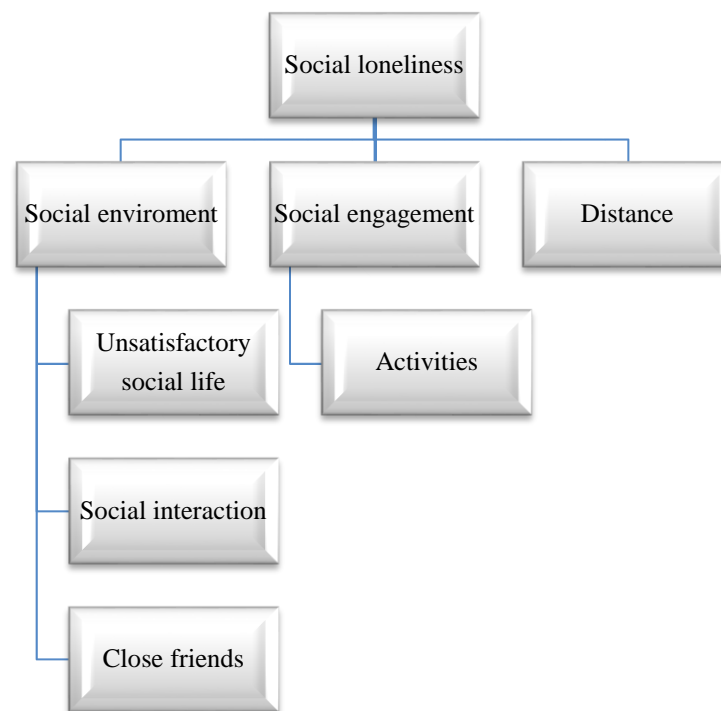


Figure 14: Emerged sub-themes for social loneliness

10.3.1.1 Social environment

An adequate social environment, both quantitatively and qualitatively, may positively impact upon experiences of loneliness. However, participants seemed unable or at least partially unwilling to maintain a satisfactory social environment. This resulted in participants'

unsatisfactory social life which exposed them to experiences of social loneliness. Three sub-themes emerged in relation to social environment which further describe this aspect of social loneliness.

a) Unsatisfactory social life

The unmet need to form or maintain an adequate social life was depicted by several participants who stated that they do not go out regularly or at all, and they are unable to participate in activities they used to before admitted to the nursing homes.

“Overall I’m not going anywhere” (Hope, age range: 60-70 years old)

“I’ve got nothing to do...nothing nothing nothing to do, nothing. Well I don’t go anywhere. I was told that would be taken out but we don’t go out. We don’t go out...Me and my wife could have gone to do shops on our own. A bit shopping, but we didn’t. I haven’t been out at all this year” (John, age range: 71-80 years old)

“I haven’t been out. The places I have been to, I don’t know any of these places, I used to but I haven’t been there anymore. So I don’t go now anywhere. Well I don’t do a lot I used to. You sit here like a bug, I mean you’ve got nobody, you feel nobody” (Janis, age range: 81-90 years old)

b) Social interaction

Participants’ inadequate social environment was also depicted by their lack of opportunities for social interaction with others in the nursing home. Often their social interaction was limited to visiting family members which could not prevent their feelings of ‘social emptiness’. Participants’ longing for social communication to others was frequently apparent. For example, one participant wrote letters and listened to the radio, while another participant left her room door open so that she could see people passing by in order to talk to them.

“See I don’t see many people. I don’t get many people to speak to ...No I am not so isolated cause I try I try listening to the radio. What I’ve listened to helps me to sort of communicate with the people I write to. When I do get around to writing ” (Hope, age range: 60-70 years old)

“...no, no I got people back home...I don't think they really wanna know...Some people have their own life to do they don't think about other people...” (Janis, age range: 81-90 years old)

“I don't have that many friends in here because I haven't made any... I be quite...I just (he cries) I could make friends...because I don't mix, I never mixed, because if I mixed in the beginning probably I would be alright there” (David, age range 81-90 years old)

Participants' limited communication with staff members also seemed to influence their experiences of social loneliness. One example for this was Silvia (age range: 60-70 years old), who described her willingness to interact with staff members, yet staff members' workload became an obstacle.

“I say to them sit here on the bed for 5 minutes which they do...it's only if she's got the time to do it, sort of thing, you know how busy are these people, don't you?”

c) Close friends

While the majority of Participants stated that they had *'someone that they can talk to'*, very few stated that they had close friends in the nursing home. This is also an example of Participants' unsatisfactory social environment that contributed to experiences of social loneliness. Even when participants did state they had close friends within their nursing home, social loneliness remained due to their friends' poor health'. An example of this comes from Janet (age range: 60-70 yearsold):

“I do yes (feel lonely) because one of my friends is not very well, she said she has a feeling that her body is being burnt, (and) sometimes she wants to be alone.”

10.3.1.2 Social engagement

Unfulfilled needs for social engagement, that is, the need of being actively involved within and between social groups or the community, may influence one's experiences of loneliness. One sub-theme emerged in relation to social engagement: activities (figure 15).

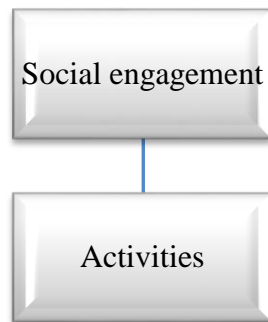


Figure 15: Emerged sub-themes for social engagement

In this study's context, non-participation of social activities jeopardised older adults' opportunities for social integration, that is, to feel part of a social group, which intensified experiences of social loneliness. Many of the older adults stated that were unable and/or reluctant to get involved into any activities provided by the nursing home. In addition, some of them were unwilling to leave their room, while others attended only the activities being compulsory in nature. The following excerpts illustrate this theme:

"Well I don't do a lot I used to sit here, and read, if you can, if your eyes are OK, if everything is ok, and put myself together to do things, but otherwise luv there is not lot to do" (Janis, age range 81-90 years old)

"I'm too old to attend all of these (activities). No I'm too old, most of them are old in here. I listen to the television and that's about it. I just sit here (his room), and watch the television" (David, age range: 81-90 years old)

"I can't do much you see. I sometimes get very (sad) because I can't do much" (Ian, age range: 91-100 years old).

“...I do try and make an effort, I go over to the occupational therapy cause It’s always been compulsory to occupational therapy... I don’t want to go out at all really” (Hope, age range: 60-70 years old)

10.3.1.3 Distance

Physical distance was key aspects of participants’ experiences of social loneliness. Being forced to reside far away from the environment participants had lived for many years negatively influenced social opportunities and exacerbated feelings of loneliness. This theme was apparent throughout the majority of the interviews. For example:

“Well luv, I say straight, I’d rather much rather being in my own home, I tell you that straight, there is nothing I miss more than that. You don’t like living anywhere, I’d rather be where I always being...I don’t like pushed away but what can you do?” (Janis, age range: 81-90 years old).

“I wasn’t very keen on it...I don’t think many people would, but is just one of these things that you just don’t know, you know, where you are going to end up” (Silvia, age range: 60-70 years old).

“Not great not great (living far away from his family). I know the people here do wonderful, I know that, but is just something about no; It hurts me.” (David, age range: 81-90 years old)

10.3.2 Emotional loneliness

Emotional loneliness results from the unfulfilled need of intimate relationships. Lack of significant others and lack of connectedness triggered emotional loneliness (for an overview see chapter 3). Three main sub-themes were identified in relation to this concept: integrated family life, immensity of loss, and desire for closeness (figure 16).

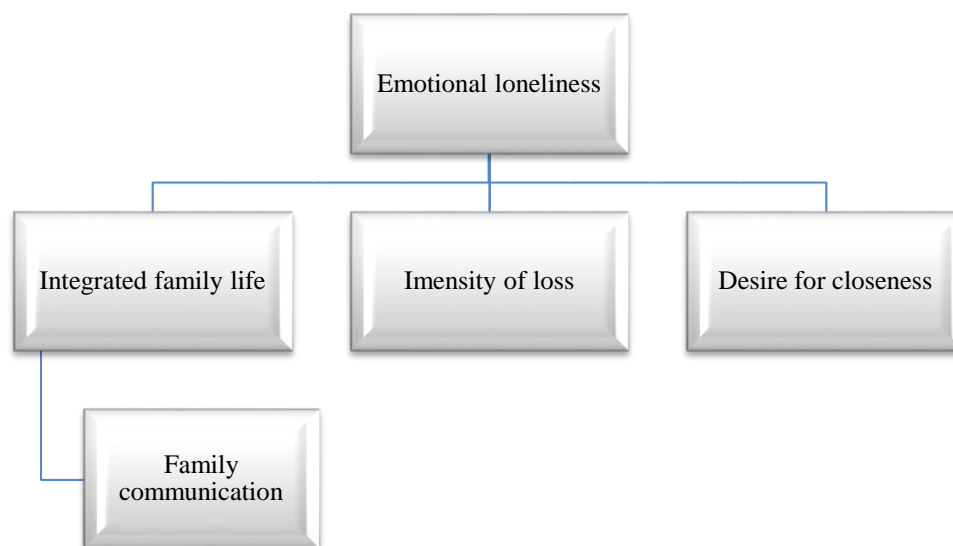


Figure 16: Emerged sub-themes for emotional loneliness

10.3.2.1 Integrated family life

Maintaining an active role within family life was important for the participants. Therefore the unfulfilled need of maintaining an integrated family life revealed experiences of emotional loneliness. One example for this comes from Hope (age range: 60-70 years old), who stated:

“If I just saw them occasionally, it will be something towards family life. Something towards family life, I can’t tell it’s family life.”

My brother visited me last Wednesday....he is going away again on the 12th of October to celebrate his 65th birthday. They are always flew far away all the time. They are not near or anything...Has something to do with family life. I miss that really. Because I say could I come down and stay a couple of days meet the family and she said that’s to be considered you know. That’s how she goes on.”

a) Family communication

Family communication also played a key role in the fulfilment of intimacy needs. Absence of or unsatisfactory communication with family members contributed to emotional loneliness.

For example, several participants highlighted that their children and other relatives do not ‘bother’ to visit them:

“I haven’t seen them at all this year. I haven’t seen the boys for years. When I was put in hospital they never came to see me, nor did my wife” (John, age range: 71-80 years old).

“I have two children...they don’t come and see me in here. I’m a bit upset about it. If they don’t wish to visit me at the home they could at least tell me to have a couple of tea, couldn’t they? I’ve done lots for them over the years” (Janet, age range: 60-70 years old)

“...and it’s just left is my brother and sister really, and I haven’t any communication at all with them on the phone” (Hope, age range: 60-70 years old)

10.3.2.2 Immensity of loss

Grieving the loss of a spouse increased the risk and severity of emotional loneliness. For example:

“She died, I forget how many years ago, but it broke me. If you know what I mean. It did. It broke me when she died. I still have a tear or two when I come and look out of the window. I can’t help it, cause I’ll never forget her, I’ll never forget her” (Ian, 91-100 years old)

“I said well she died ...I feel sad every minute a day because she is not with me anymore...I just cry and get over it, just cry cry... Get my wife back. Yea. That’s it” (David, age range: 81-90 years old).

The lack of significant others, either due to loss or because of physical or emotional distance, also triggered experiences of emotional loneliness. For example, one participant (George, age range: 60-70 years old) highlighted how much he misses his parents, and talks about his bereavement therapy that helped him cope with his father’s death.

10.3.2.3 Desire for closeness

The interviews also revealed that participants who were living in the same nursing homes with their spouses also encounter emotional loneliness. This results through their unfulfilled need for closeness, both physically and emotionally. An example for this is John (age range: 71-80 years old), who describes his agony of not being able to be intimate with his wife although sharing the same facilities:

“I was not allowed even to hold her hand, give her a kiss, and nothing like that...I asked to see her...to be with her. No. No. Horrible. I haven't cuddled her miss, put my arms around her, feel all her little spots, you know. She is beautiful. You can't make love to your wife. I can't do that. That was years ago miss. How can I only go years ago, I don't know how long ago it was years ago.”

10.3.3 Emotional reactions

Emotional and social loneliness triggered a range of emotional reactions among the study participants. In relation to emotional reactions four sub-themes emerged; hostility, sadness, desired social isolation, boredom (figure 17).

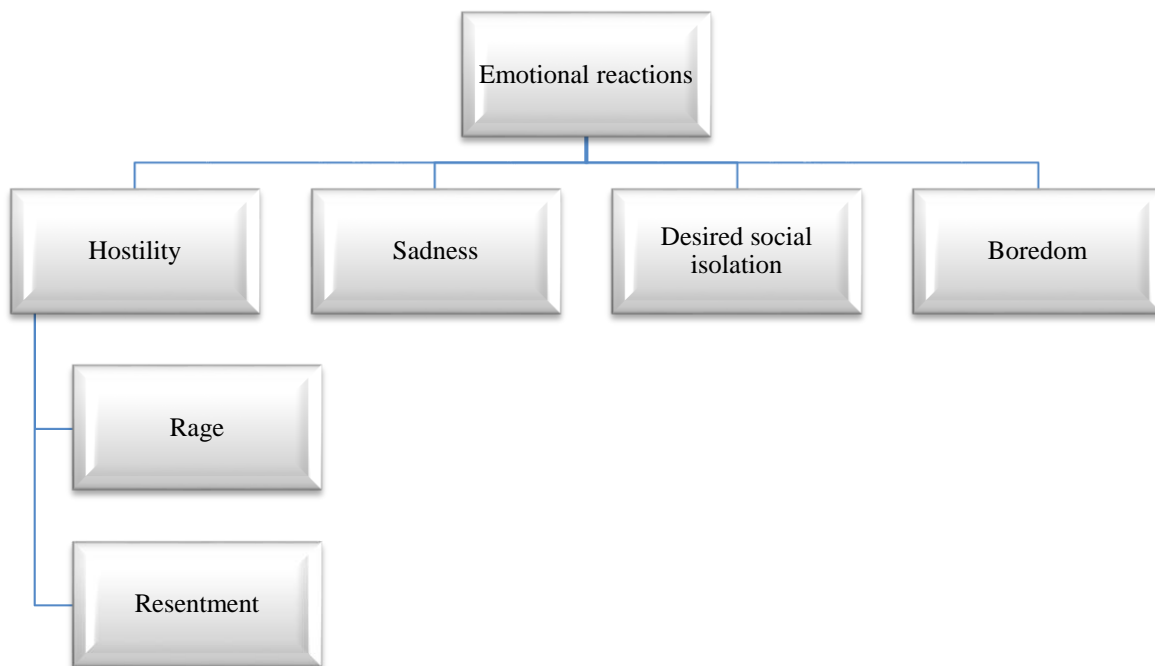


Figure 17: Emerged sub-themes for emotional reaction

10.3.3.1 Hostility

a) Rage

Although it was not always explicitly stated, some participants were angry and highly unsatisfied with the quality of care and the quality of life in their nursing home, often expressing rage towards their nursing home. For example, one participant (John, age range: 71-80 years old) was angry as he stated “*nobody cares about his inability to use his legs again*”, “*he don’t get anyone to get him in the fresh air*” and “*these people (people with mental illness) need to be cared for, and I don’t think this place cares for anybody*”.

b) Resentment

The majority of the participants state that the life in the nursing homes is overall good. However, loneliness also triggered feelings of resentment towards the nursing home environment. An example of this also comes from John (age range: 71-80 years old) who stated:

“I hate it here miss”

10.3.3.2 Sadness

Many participants expressed sadness during conversations centred on their emotional and social loneliness in their nursing home, feeling far away from their previous home, and missing their loved ones including spouses who have since died or families that failed to connect with them enough.

10.3.3.3 Desired social isolation

Participants showed a strong desire for the need to sometimes be isolated or alone. This included a willingness to stay in their room by themselves, and a reluctance to become close to or communicate with other residents in the nursing home.

“I don’t want a lot of noise and I don’t want disturbance in my room. People coming and going all the time and I prefer to cut myself off and just think quite. My thoughts really. You know what I mean? My thoughts” (Hope, age range: 60-70 years old)

“I don’t go to many of them (activities)...I mean some of them say you are here by yourself Silvia, but that don’t bother me, I do like my company” (Silvia, age range: 60-70 years old)

10.3.3.4 Boredom

Participants also experienced feelings of boredom due to their limited social interaction with others. This was expressed during conversations about ‘not doing much’ in the nursing home, and that they ‘don’t go anywhere’. Other times it was expressed more explicitly. For example, Janet (age range: 60-70 years old), described living in the nursing home as “*a bit boring*” because of the “*shouting that’s going on*” from the other residents.

10.3.4 Coping mechanisms

Participants’ experiences of loneliness trigger their need to develop coping mechanisms. Participants describe different ways of countering loneliness. In relation to cope mechanisms three sub-themes emerged; religiousness, television, open door (see figure 18).

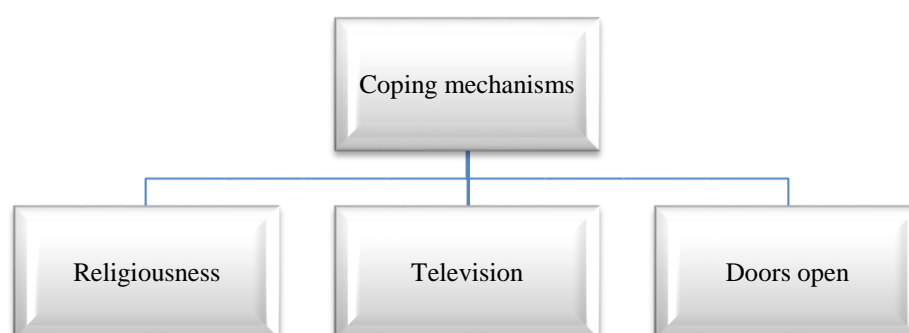


Figure 18: Emerged sub-themes for participants’ coping mechanisms

Participants religiousness serve as a coping mechanism so that to alleviate their experiences of loneliness, others prefer of watching television in their rooms, while others adopt more practical and immediate forms such as to leave their rooms’ door wide open so that to see people.

“I got Jesus Christ in my life. I try to think I have you know ...I’m not getting paranoid about anything, I just think I’ve got joy in my heart to times” (Hope, age range: 60-70 years old)

“I watch television” (David, age range: 81-90 years old)

“I'd like the door being open I don't like it being closed and that you know...they then pull my armchair out like near where you are, and its so that I can see people going by and that and they come in and they say you are alright Silvia and things like that” (Silvia, age range: 60-70 years old)

10.4 Experiences of self-stigma among mentally ill older adults in nursing homes

The qualitative analysis regarding self-stigma revealed that older adults who had no insight into their illness do not (explicitly) seem to experience self-stigma. The analysis on experiences of self-stigma is therefore limited among a small number of older adults (n=3) who had insight into their condition.

Regarding older adults' experiences of self-stigma three main themes emerged: rejection, isolation, inferiority. Figure 19 and section 10.4.1 present and discuss the themes and sub-themes of the qualitative analysis.

Overall three main themes emerged regarding older adults' understanding and views about mental illness; attitudes towards mental illness, perceptions towards mental illness, behavioural reactions. These themes were further analysed into sub-themes. Figure 20 and section 10.4.2 present and discuss the emerging themes and sub-themes. All themes build upon the socio-cognitive self-stigma model, and this study's literature review.

10.4.1 Insight into mental illness and experiences of self-stigma

As stated earlier the analysis regarding experiences of self-stigma is limited among older adults who were aware of their condition (n=3). Insight into mental illness therefore seemed to influence experiences of self-stigma. The themes and sub-themes are below presented (figure 19).

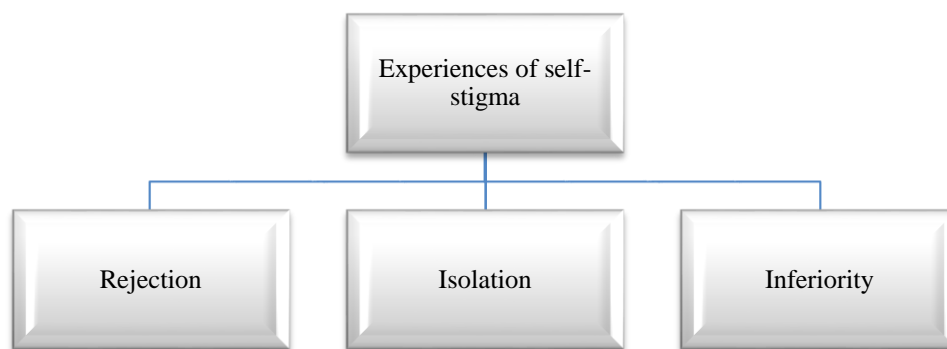


Figure 19: Emerged themes for experiences of self-stigma

a) Rejection

Participants who were aware of their illness experience self-stigma through rejection from their family members. This is depicted from two participants who state:

“...my husband left me, we are still sort of married, but he moved out...he run away. Now he lives too many miles away” (Janet, age range: 60-70 years old)

“...When I used to go down years ago and knock on the door she sent me away. I get a taxi and go down she says off you go you ain't coming in here you know. It was like that with me. She treated me as if I couldn't have anything to do with her and her family (cause or as if) I was psychiatric or something. She held against me. Made me feel rejected really.” (Hope, age range: 60-70 years old)

b) Isolation

Experience of self-stigma is also depicted from participants' feelings of isolation. Participants reveal their strong reluctance to communicate and interact with other residents, and people in the community.

“Sometimes I just hurry up and go upstairs, take the tracks and go upstairs by myself. I am isolated...I've tried to be compliable with them (other residents), you know. I've tried to be sociable” (Hope, age range: 60-70 years old)

“I was quite bubbling person, chatting, I got depressed and didn’t want to go out. I just stayed in bed, stayed in the house” (Janet, age range: 60-70 years old)

c) Inferiority

Participants also experience self-stigma through the endorsement and application of the negative perceptions that the public holds and attaches towards people with mental illness. For example, one participant perceived himself as a burden to his family because of his condition, while another participant felt inferior to clinical staff members.

“It’s not exactly good experience (living with mental illness). Cause when I was living with my parents, they didn’t sort of understanding at the time and must have been bad for them” (George, age range: 60-70 years old)

“I mean I was considered myself a patient you know. I had to go there as a patient and there was a staff that was superior to me. I’ve tried to work out” (Hope, age range: 60-70 years old)

10.4.2 Understandings and views towards mental illness

The majority of the participants were found to hold similar attitudes and understandings towards mental illness regardless of having or not insight into their condition. Three main sub-themes emerged; perceptions, attitudes, and behavioural reactions. The sub-themes were then further categorised. All themes and sub-themes are below discussed and presented (figure 20).

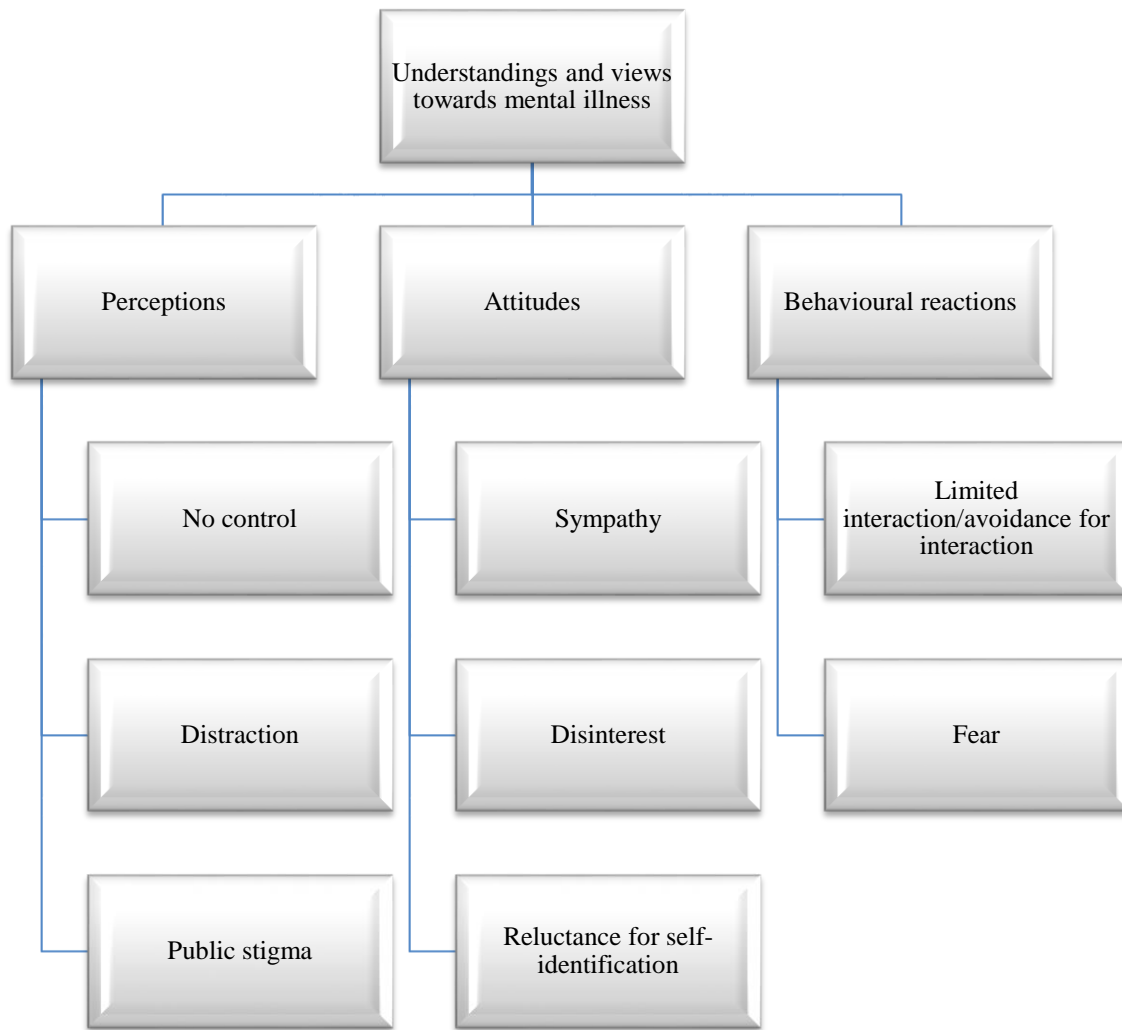


Figure 20: Emerged sub-themes for understandings and views towards mental illness

10.4.2.1 Perceptions

In relation to perceptions three sub-themes emerged; no control, distraction, and public stigma. The sub-themes are below further discussed and presented.

a) No control

Participants perceived people with mental illness as aggressive, violent, and under no control. Many participants talked about incidences of violence from other residents who they thought of suffering from mental illness. Participants also stated that some of the residents often were shouting, and/or were throwing objects to the rest of the residents.

“It’s not many of them now. Just the few of the men. Because they get out of control. They hit and they got knives up and things. Yes they do” (Hope, age range: 60-70 years old)

“Well there is one man. He is always hungry, he got no patience and he says what time is food, about 5 o'clock, banging the furniture and throwing things” (Janet, age range: 60-70 years old)

b) Distraction

The incidences of violence or aggressive behaviour may trigger feelings of distraction to the rest of the residents. For example, participants preferred rather to stay in their rooms instead of attending activities or mixing with the residents who became aggressive.

“Sometimes. I am not always that good to. Sometimes I get a bit upset with them. But most of the times I'm alright” (George, age range: 60-70 years old)

“It’s distracting really” (Hope, age range: 60-70 years old)

c) Public stigma

Some of the participants talked about the negative views that the public holds towards people with mental illness. Specifically one participant during the interview referred to the potentially social embarrassment of living with mental illness, while she pointed out that people with mental illness are perceived as ‘low type’ which causes people to ‘hold back from them’.

“You are the lowest type unless you do something for yourself jobs and things, try to go to work and support yourself and you know develop some friends around you and get interests. People would hold back from you. if there is a rumour or something ‘oh you are a patient, she is a patient’; she is a social embarrassment in the community or something” (Hope, age range: 60-70 years old)

Another participant stated that there is a stigma towards mental illness in the community which probably results from or is caused by peoples' non-understanding towards the condition.

“Well, there is a bit of a stigma attached to in the outside community. Yea. Cause, they probably can't understand what is about really” (George, age range: 60-70 years old)

10.4.2.2 Attitudes

In relation to attitudes three sub-themes emerged; sympathy, disinterest, reluctance for self-identification. Each of the sub-themes depicts the attitudes of older adults towards mental illness. Each sub-theme is discussed separately.

a) Sympathy

Sympathy was one key aspect of older adults' attitudes towards people with mental illness. The majority of the participants seemed to sympathise the mentally ill because *“they didn't choose it”*, to become mentally ill, but it was something that happened to them, and others because *“they are in the same boat as them* (older adults experiencing mental health problems)”.*”*

b) Disinterest

Older adults also revealed a strong disinterest about the problems that people with mental illness might experience and cope with. Some participants thought mental illness is the result of the aging process, while others believed that people with mental illness should be looked after by their families. An example for this is John (age range: 71-80 years old), who argues:

“I don't worry about them miss. They don't worry about me, why should I worry about them? Everybody here should have a family.”

c) Reluctance for self-identification

Participants were strongly reluctant to identify themselves as people suffering from mental illness. It is worth mentioning that the majority of them seemed to be quite negative towards the possibility of suffering from mental illness. This was apparent throughout the interviews. For example, when participants were asked to state their opinion about mental illness, their

first reaction was to clarify that they did not suffer from the illness. One of the participants even stated:

“No thank God. Well I’ve never told I have mental illness” (Janis,
age range: 81-90 years old)

However when participants was assured that the interviewer did not imply that they suffer from mental illness, they were more willing to start a conversation about it and express their views on the matter.

10.4.3 Behavioural reactions

In relation to behavioural reactions two sub-themes emerged; limited/avoidance interaction, fear (figure 21). The themes and sub-themes explain the way older adults’ behave towards people with mental illness. Each theme is separately discussed.

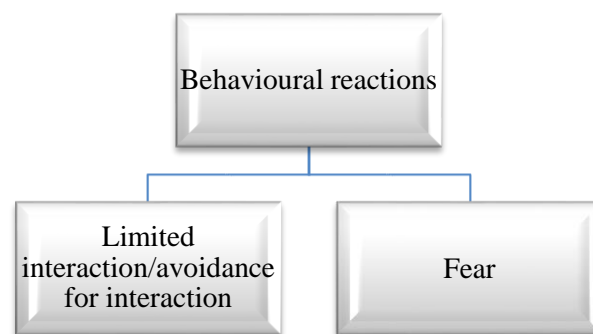


Figure 21: Emerged sub-themes for behavioural reactions

a) Limited interaction/avoidance for interaction

Participants preferred to keep distance from older adults who suffer from mental illness. The majority of the participants stated that they were unwilling to mix older adults experiencing mental health problems. Also participants argued that being in the same room with older adults who suffer from mental illness is upsetting, and at times scare because most of them cannot control themselves.

“They are poor, so you are seeing them getting old and foggy and you think oh dear. There was a poor women that used to be up there a long time I think she is still there but she lies in the chair

with her mouth wide open you feel so sorry for people when you see them” (Janis, age range: 81-90 years old)

“They are aged sort of thing and used to upset me, so I didn’t bother to go anymore in there (activities room)...sometimes some other ladies used to shout and scream and they cannot help themselves and the staff got them out of the room sort of thing” (Silvia, age range: 60-70 years old)

“He throws things from the door to me. Things that, you know. I don’t mix with anybody here” (John, age range: 71-80 years old)

“No I’ve never get involved with any of the men really, you know, to talk to. Just John he gets all psychotic and threatens people...Problems with him, you know.” (Hope, age range: 60-70 years old)

Some participants also argued that older adults with mental illness do not wish to be mixing with other people, they usually stay in their rooms, while they are unable to maintain a conversation.

“They usually are in their place, their own. They don’t mix, no no they don’t” (Ian, age range: 91-100 years old)

b) Fear

The majority of the participants did not feel frightened of the residents who suffer from mental illness, yet two participants disclosed feelings of fear. Older adults who were suffering from mental illness found it difficult to keep control over their condition which resulted to incidences of violence. The latter usually caused emotional reactions to other residents who could not handle an intense environment. The former participants were living in a nursing home which solely specialises to mental health care.

“Frightened, yea, because the lady throw the table to me once... and all the shouting that’s going on” (Janet, age range: 60-70 years old)

“Well I’m frightened of them enough. I’ve been never hurt so far but I’m frightened them over the meals. I want to rush out you know run out to town. It’s just the reaction to it. It’s not many of them now. Just the few of the men. Because they get out of control. They hit and they got knives up and things. Yes they do” (Hope, age range: 60-70 years old)

10.5 Culture

In relation to cultural values two main themes were identified; family relationships and valuing family relationships (figure 22). The former themes describe participants’ cultural perceptions and environment.

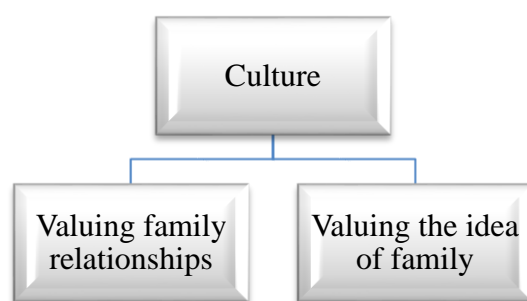


Figure 22: Emerged sub-themes for culture

a) Valuing family relationship

During discussions about the nature of their family relationships participants demonstrated a strong desire and willingness to maintain close family bonds. The agony of losing family connectedness was depicted from one participant who stated:

“I felt lonely, because I thought they won't come and see me”

(Rose, age range: 71-80 years old)

b) Valuing the idea of family

Family connectedness was a key cultural value. Almost all participants claimed that family connectedness was one of the most important values in life.

10.6 Discussion of qualitative findings

Interviews were carried out with older adults with mental health problems in nursing homes to explore their experiences of loneliness and self-stigma within their cultural context. Using interpretive phenomenological analysis the experiences of loneliness and self-stigma, and potential differences between participants were explored. The views of participants, based on their experiences, provided useful insight into experiences of loneliness and self-stigma and advanced our understanding of the concepts among this population. The findings also resulted to a new theoretical model that explains loneliness and self-stigma among this population. The findings of the qualitative phase and the new theoretical model are herein discussed.

10.6.1 Discussing experiences of loneliness

The findings of this study revealed that experiences of loneliness (both social and emotional loneliness) are present among this sample. More specifically, experiences of loneliness are complex, multifaceted and powerful to wellbeing of this group. The findings are in line with both the quantitative results of this study and previous empirical research on loneliness (Roos & Malan, 2012; Tse *et al.*, 2013; Drageset *et al.*, 2013; Mezuk *et al.*, 2014) among older adults. For example, Slettebø (2008) examined nursing home residents' perceptions about their lives in nursing home settings. The author interviewed 14 residents living in Norwegian nursing homes. The findings of the qualitative analysis revealed that residents felt safe in the nursing home, yet lonely. Loneliness is therefore a key issue among older adults in nursing homes both inside and outside the UK context. The findings of the qualitative arm of this study along with the quantitative results provide useful information about loneliness among this population, while advance our understandings on the topic. Also the qualitative findings align with Weiss's (1973) theoretical model of this study, and give weight to the Victor *et al.*'s (2005) argument that the distinction between social and emotional loneliness has advanced loneliness ageing literature.

Social loneliness was a key aspect of older adults' experiences of loneliness according to this study's qualitative findings. Older adults with mental illness in nursing homes experienced social loneliness through their limited social environment. This was apparent through their inability to maintain activities outside the nursing home such as shopping, to participate in activities they used to participate before admitted to the nursing home such as doing the

garden, and to visit places they used to out of the nursing home. All the above limited their chances to form an adequate social network, and thus maintain adequate social relationships. Older adults' desire for communication with others and lack of close friends also highlighted their feelings of 'social emptiness'. Having an unsatisfactory social environment therefore, influences feelings of social loneliness among this population.

Lack of social engagement through participants' unwillingness to take part in nursing home activities also exacerbated experiences of social loneliness among them. For example, some older adults were reluctant to leave their rooms, while others participated only in the activities which were compulsory. Consequently participants experienced social loneliness due to their unfulfilled need for social engagement. Also, older adults' physical distance intensified experiences of social loneliness. More specifically, this study's sample were unhappy to move in the nursing homes and be away from their previous environments. By doing so, they might have lost their existing social connections, and thus spoiled their social integration, which intensified their experiences of social loneliness. Quantitative studies support the former findings. For example, de Jong Gierveld *et al.*, (2015) examined key detractors of loneliness in a sample of 3,799 Canadian older adults (+65). Data were used for the Statistics Canada's General Social Survey, Cycle 22. They found that both social network size and composition, as well as satisfaction with network contact, influence feelings of loneliness among older adults.

Unfulfilled needs of intimate relationships influenced older adults' experiences of emotional loneliness. This was particularly evident during discussions about the lack of close family life and communication, loss of loved ones, and the desire for closeness. This supports Stevens and Westerhof (2006) who found that older adults who reported experiencing less companionship and support from their spouse felt lonelier compared to their counterparts with higher levels of companionship. As the findings of this study revealed these themes are also powerful and significant for older adults with mental health problems in nursing homes. This highlights the need to provide adequate emotional and social support to this population and to assure a satisfying degree of companionship among them so that to alleviate experiences of emotional loneliness.

In addition, emotional loneliness was present among older adults who shared the same nursing facilities with their spouses because of lack of intimacy (both physical and emotional). de Jong Gierveld *et al.* (2009) showed that older adults who evaluate their current

sexual activity as not pleasant or not applicable are more likely to experience strong emotional and social loneliness. The latter is supported by the findings of this study, which highlight that engagement in sexual activity is equally important to older adults with mental health problems in nursing homes. As discussed in section 8.7.2 existing national policies aim to reduce social isolation among long-term care residents, and not loneliness. However, the evidence in this study showed that older adults in care experience social and emotional loneliness which future policy should explicitly recognise.

Gender has repeatedly been found to play a key role in feelings of loneliness (e.g. Cohen-Mansfield *et al.*, 2009; Simon *et al.*, 2014) among older adults. Similarly the findings of this study identified gender differences in emotional loneliness among this sample. More specifically, men reported intense feelings of emotional loneliness because of the loss of their spouses compared to their female counterparts. Although the sample consisted of both female and male widowed participants, intense experiences of emotional loneliness were reported solely from the male widowed participants. One possible explanation is that males lose key roles due to the constant life changes they experience. When older adults are unable to perform important roles because of losses and/or poor physical health might experience higher emotional loneliness. Another possible explanation is because of the gender differences on attachment security, and discrete emotions in later life. The literature suggests that gender patterns of attachment are linked to patterns of emotional experiences that affect one's emotional well-being. Consedine and Fiori (2009) in a sample of 616 participants from middle age and later life found that attachment security relates to feelings of joy, interest and marginality among men. Losses that affect patterns of attachment security can therefore contribute and/or result to intense experiences of emotional loneliness among male older adults.

Rage, resentment, sadness, desired isolation and boredom were key emotional reactions of experiencing loneliness among this population. More specifically, older adults often felt resentful and sad because of living in the nursing home. Older adults may not think of nursing home as their home or as a place they could live happily for the rest of their lives, which partially explains reactions of resentment towards the new environment. Kvaal *et al.* (2014) interviewed 101 older adults in Norwegian geriatric wards and identified similar emotional reactions such as anger and sadness. This study's sample also revealed feelings of boredom. Older adults both because of physical and mental health problems might be unable to participate in activities, and therefore to form an adequate social environment. This

exacerbates feelings of boredom which may influence their experiences of loneliness. Older adults also remained isolated from peers which may intensify experiences of loneliness among them. Desired social isolation does not always indicate experiences of loneliness (Tzouvara *et al.*, 2015), however a particular context may influence our choice of becoming socially isolated and therefore experiencing loneliness. For example, the nursing homes approached in this study provided care to older adults with different types of mental illness (e.g. depression, schizophrenia). Older adults living in these settings, therefore, often shared the same environment and lived in the same ward with older adults who may experience severe forms of mental illnesses. This may intensify older adults' reluctance to interact and communicate with their peers. Therefore, older adults may become socially isolated not always because they wish to do so, but also because of the context of the nursing home itself which may lead to older adults' social isolation, and therefore intensify experiences of loneliness among them.

Loneliness has been found to result in specific coping mechanisms. For example, participants were found to leave their doors open and watch television in an attempt to alleviate loneliness. Some other participants stressed their connection with God and revealed the key role of religiousness in coping with loneliness. This comes in line with the quantitative results of this study and the loneliness literature (e.g. Harrison *et al.*, 2001). More specifically, in a recent meta-analysis of the literature, Sherman *et al.* (2015), investigated how religion and spirituality associate with cancer patients' social health (n= 4,277); that is, their capacity to remain actively engaged in social roles and to feel meaningfully connected with others. The authors identified that better social health was associated with stronger spiritual well-being. Also participants with more benign images of God (such as perceptions of a benevolent rather than an angry or distant God), or stronger beliefs (such as convictions that a personal God can be called upon for assistance) were actively engaged in social roles and had meaningful connections with other. Therefore, religiousness and spirituality are two coping mechanisms towards loneliness since they help patients to maintain better social health.

The findings of the qualitative phase are important because they provide key aspects of experiences of loneliness among this population (emotional and social loneliness). Therefore, they advance our understandings on the topic and highlight the need to theoretically re-form loneliness. That is, the need to develop theoretical models that provide a 'multifactorial' explanation of loneliness. The findings of this study (qualitative and quantitative) give weight to the former proposition because they reveal the key role of a number of socio-demographic

factors in explaining loneliness, and highlight the need to be acknowledged when loneliness is explored among this population.

10.6.2 Discussing experiences of self-stigma

The level of insight into one's mental illness was found to be a key aspect of participants' experiences of self-stigma. More specifically, perceptions of inferiority, isolation, and rejection because of mental illness influenced experiences of self-stigma among this study's sample who had insight into their illness. The findings also showed the relationship between experiences of self-stigma and loneliness through feelings of rejection and isolation. The findings therefore provide significant grounds for developing theoretical models that explain the relationships between self-stigma and loneliness among this population. In addition, as discussed in section 8.7, a number of previous quantitative studies revealed that insight into illness influence levels of self-stigma. Similar findings were reported by the qualitative arm of this study. The findings therefore underline the importance of developing theoretical models that include the concept of insight into illness in moderating the self-stigma experience among this population. This is important given that the majority of the theoretical approaches towards self-stigma may acknowledge the role of stereotypes (e.g. Corrigan & Watson, 2002) into the process of self-stigma, but fails to document the key role of insight into illness. Participants revealed commonly held views towards mental illness regardless of their level of insight. Specifically, participants perceived people with mental illness as violent and out of control, while they perceived their behaviour as distracting. Overall, participants felt sorry for older adults who are experiencing mental health problems, yet they were disinterested in the difficulties that may face and cope with.

In addition, participants were reluctant to self-identify themselves as mentally ill. This refers also to participants who had insight into their illness, since their first reaction was to be unwilling to identify themselves as such. This might reveal feelings of shame - a form of self-stigma. In addition, participants reported a strong unwillingness to socially interact with older adults experiencing mental health problems- a quite contradictory behavioural reaction since all participants of this study were found to experience mental health problems. One explanation for this is that the majority of older adults participating had no insight into their condition and were unwilling to identify themselves as mentally ill. Finally, older adults felt frightened of residents who were suffering from mental health problems. The latter increased their reluctance for social and emotional interaction. This has been repeatedly reported from

studies examining public stigma towards mental illness (e.g. Economou *et al.*, 2012). It could be argued therefore, that older adults with mental health problems in nursing homes are stigmatising against their peers who are also experiencing mental health problems and residing in nursing homes. Older adults' lack of awareness and knowledge may result to misconceptions about mental illness, and therefore may increase negative attitudes towards older adults with mental health problems. It is worth mentioning therefore that interaction with people with mental illness alone is not enough to tackle stigmatising attitudes from occurring.

The findings revealed three important aspects in relation to experiences of self-stigma.. Insight into illness was key on understanding the self-stigma process among this population. This is important as to re-think the theoretical underpinnings of self-stigma, which could potentially explain variations at the levels and experiences of self-stigma (e.g. low levels with a tendency to moderate/high) among this population. Another key finding of this study was the relationship of self-stigma and loneliness. As stated earlier this relationship is explained through participants' experiences of isolation and inferiority. This is significant because it provides grounds for developing theoretical models that explain the relationship between the two concepts. Finally the findings revealed that this population feel frightened of, is reluctant to socially interact with, and finally stigmatises against older adults with mental health problems in nursing homes. Therefore, mental health literacy, that is the knowledge and understanding of consequences and impacts of mental health problems, is required in order to tackle stigmatising attitudes from occurring among this population.

10.6.3 Experiences of loneliness, self-stigma, and culture

This study's population were found to value family relationships and to prioritise the idea of family connectedness. According to the literature review of this study, collectivists are more likely to prioritise family relationships and inter-dependence compared to individualistic older adults (see chapter 5). More specifically, people subscribing to collectivistic values give priority to family inter-dependence and in-group connectedness over individual goals (Triandis, 2001). However, the findings of this phase did not explicitly indicate subscriptions to specific collectivistic and individualistic cultural values. Older adults in nursing homes, however, at the individual level of cultural subscriptions were found to prioritise family interconnectedness and relationships which is one key element of collectivism (compared to individualism).

The findings revealed that the majority of the participants have close relationships with their family members, while they maintain close family bonds. Valuing family connectedness and relationships was key even among participants who had limited or no communication with their family members. Therefore, family relationships and connectedness seems to play a vital role in many of the participants' lives. According to this study's findings limited and/or lack of family communication intensify participants' experiences of emotional loneliness. The latter was highlighted by the majority of the participants who believed that family is an important value in life and family inter-connectedness is something that "... *misses really...*" in the nursing home. Therefore, limited family interaction influences experiences of emotional loneliness, especially among collectivistic older adults who prioritise family connectedness and close family relationships. The findings of this study, therefore, revealed that this population is prone to experience emotional loneliness when their inter-relationships and inter-connectedness with family members stop existing and/or are inadequately met. Therefore, emotional loneliness seems to relate with cultural values at the individual level among this population.

This is significant in theorising how culture inter-relates with emotional loneliness and of course explaining experiences of loneliness among this population. The relationship of emotional loneliness with collectivistic cultural values could partially explain why collectivistic oriented countries experience higher loneliness compared to individualistic-oriented ones (Brohan *et al.*, 2010), and of course it could partially explain within-cultural variations in loneliness (de Jong Gierveld *et al.*, 2015). Given the findings of this study and the strong indications of within-cultural variations on loneliness, it is important to start conceptualising loneliness in relation to peoples' cultural values.

It is important to highlight here that no direct inter-relationship between cultural values and experiences of self-stigma were found. However, the absence of direct relationships that could potentially explain within-cultural variations of self-stigma among this population does not necessarily mean that there are not any. The small number of this study could partially explain why within-cultural variations of self-stigma were not identified. According to the literature review of this study, however, there are strong indications about the potential relationships between culture and self-stigma (see chapter 5).

10.7 A new theoretical model of loneliness, self-stigma, and culture

Overall it appears that loneliness does indeed exist in this group. Older adults with mental health problems in nursing homes experience emotional and social loneliness through their unsatisfactory social environment, inadequate social engagement, physical distance, yearn for an integrated family life, the immensity of loss, and unmet desire for closeness. These aspects of loneliness result in specific emotional reactions and coping mechanisms. On the other hand, there are differences on the way this population experience self-stigma. Insight or no insight into mental illness appears to be a key factor. However, older adults with mental health problems in nursing homes share the same views and understandings towards mental illness independently of insight or no insight into their illness. This results in specific behavioural reactions. The findings highlight that specific socio-demographic factors (gender, age, and marital status) are key in explaining experiences of loneliness and self-stigma, while cultural values seem to influence experiences of emotional loneliness among this population.

The findings of both phases of this study have stressed the need for a new theoretical model (see figure 23) in explaining loneliness and self-stigma among this population. Current theoretical models conceptualise the concepts separately. However, there is an inter-relationship between them that indicates that ‘a one size approach cannot be adopted’ (Cook, 2013). One of the key implications of the proposed new theoretical model is that it not only takes into consideration already existing and well-established aspects but also highlights new key notions that explain loneliness and self-stigma among this group. This is important given the findings of both phases of this study that highlighted how socio-demographic factors, culture, and insight into one’s illness influence experiences of loneliness and self-stigma among this population. Therefore, the development of the new theoretical model, based on the findings of both phases, also explains and justifies how the two phases inter-relate in this study. That is, both phases provide useful information about the factors that influence self-stigma and loneliness among this population, and provide new theoretical grounds for future studies in the area.

Another key implication of the model is the theoretical advances in explaining the relationship between loneliness and self-stigma among this group, while it provides the theoretical platform to further examine these relationships. In addition the model provides a theoretical conceptualisation of loneliness in relation to one’s cultural values. This is key towards our understanding of loneliness given the vast amount of studies, along with the

findings of this study, that show cultural differentiations of emotional loneliness. Also a key implication of the model is that acknowledges the key role of ‘insight’ in explaining the process of self-stigma among this population. This is significant because it offers new theoretical pathways towards the conceptualisation of self-stigma. It also bridges the theoretical gaps in existing self-stigma models which prioritise ‘stereotypes’ in the process of self-stigma than acknowledge both aspects (insight and stereotypes) equally.

To sum, the new theoretical model is important because it explains and advances our theoretical understandings about the relationship between loneliness and self-stigma among this population. It also highlights the key role of culture in relation to emotional loneliness, and the key role of socio-demographic factors in explaining both loneliness and self-stigma. Also, the model acknowledges the key role of ‘insight’ in explaining self-stigma among this population by providing a new theoretical conceptualisation of self-stigma. Finally, the new model provides a new theoretical approach towards the former concepts which is significant given the increasing number of older adults with mental illness and loneliness residing in nursing homes. The theoretical model visually represents a synthesis of the key findings described across chapters 8 and 10.

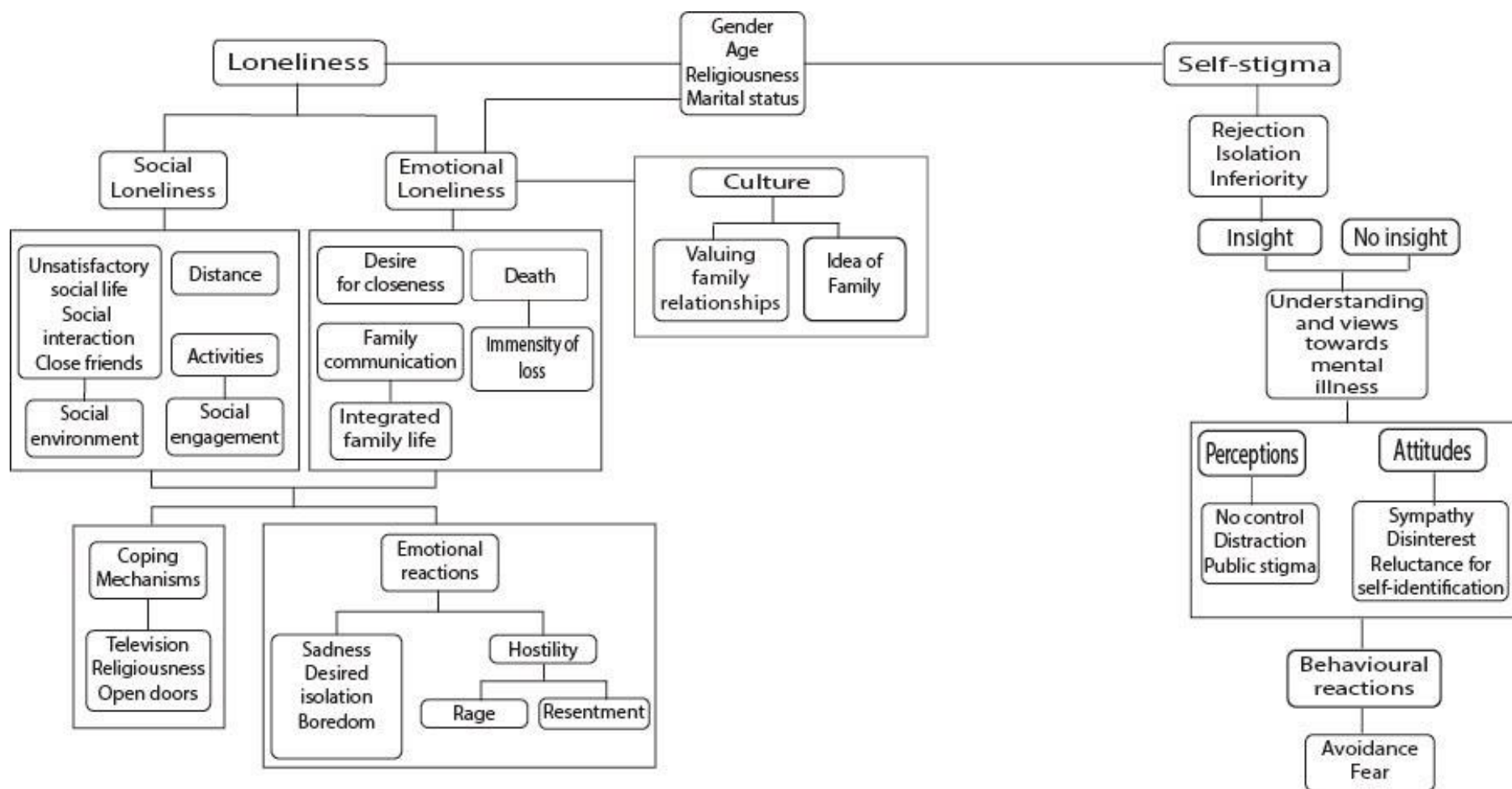


Figure 23: A new theoretical model of loneliness, self-stigma and culture

10.8 Summary

Participants experienced both social and emotional loneliness, which comes in line with previous studies, and Weiss's theoretical model. Gender was found to be a key aspect of emotional loneliness, while religiousness along with 'doors open', and 'watching TV' were identified coping mechanisms towards alleviating loneliness. Loneliness results in specific emotional reactions among participants that may trigger their feelings of loneliness to worsen. Therefore there is a two way relationship.

The qualitative findings indicated that insight or no insight into the illness is a significant aspect of experiences of self-stigma, however participants were found to hold similar views towards older adults with mental illness independently of their insight into their condition or not. Behavioural reactions towards older adults with mental illness were prevalent among participants.

In relation to culture no accurate inferences could be drawn in relation to experiences of self-stigma. However, cultural values were key aspects in relation to experiences of loneliness. Specifically, emotional loneliness interrelates with collectivistic cultural values.

The above findings stressed the importance of the development of a new theoretical model. The model aimed at explaining the process of loneliness and stigma among this population, and how this process inter-relates with their cultural context. The model was based on the key findings of this study. That is, social and emotional loneliness, insight or no insight into mental illness, understandings of mental illness, emotional and behavioural reactions, and key socio-demographic characteristics.

Chapter 11: Final discussions

This chapter discusses the broader methodological and theoretical implications. The chapter also includes a critical evaluation of the study, and critically evaluates the developed and applied recruitment protocol (described in chapter 7). The chapter then continues with the recommendations and suggestions for future action, and ends with a closing paragraph.

11.1 Broader implications of the study

11.1.1 Methodological Implications

In this study a sequential mixed-method design was adopted, with its second phase to involve an interpretive phenomenological approach. Although the research methods used are not new (Dean *et al.*, 2011; Hamdan-Mansour *et al.*, 2011; Mayoh *et al.*, 2012), the way they were combined has not been previously done in the loneliness, self-stigma, and cultural literature. The utilisation of an interpretive phenomenological approach in the second phase allowed for the in depth exploration of the concepts under examination, while minimised potential theoretical limitations in exploring loneliness. This is a significant methodological implication for future researchers because the study provides a thorough and in depth explanation and justification on the theoretical compatibility of phenomenological approaches and mixed-methods designs, and offers a methodological framework for future similar research studies.

The study also found that the recruitment of care homes is a key issue and concern when implementing research in these settings. This has repeatedly been reported by a number of previous studies (e.g. Mody *et al.*, 2008; Jørgensen *et al.*, 2014), and has been the main objective of a number of methodological papers (e.g. Davies *et al.*, 2014; Tzouvara *et al.*, in press). Prior to this study, our knowledge on the specific barriers of UK-based older adult nursing home recruitment was restricted because of the limited number of studies in these settings (e.g. NIHR School of Social Care Research 2011). Therefore, one key outcome of this study is that it complements previous research on the topic, provides significant information about the recruitment challenges and barriers to recruitment of UK-based nursing homes, and enhances our overall understanding of recruitment challenges in care settings. The proposed ‘new multi-method’ approach aims to boost researcher’s success in recruiting UK-based older nursing homes in future studies.

11.1.2 Theoretical Implications

This study represents a starting point in the investigation of the inter-relationships between mental illness self-stigma, loneliness, and cultural subscriptions. It has therefore advanced academic knowledge towards the relationships of these concepts. This is important because we are in a better position to understand how loneliness, self-stigma and culture may influence each other, and therefore to identify effective ways to eliminate their effects.

The findings of this study reveal that self-stigma and loneliness exist among this population. In addition, cultural subscriptions were found to relate to experiences of emotional loneliness, while socio-demographic (age, gender, marital status, religiousness) characteristics seemed to explain loneliness and self-stigma among this population. The findings of this study are important because they provide significant information about the prevalence of loneliness and self-stigma among this population, shed more light in the experiences of loneliness and self-stigma among this population, while constitute the platform for further investigation on the topic. Also, the findings highlight the urgency to further study on the prevalence of self-stigma and loneliness among this highly vulnerable population, given the limited existing research. This is important because of the negative effects that loneliness and self-stigma have upon peoples' lives. For example, loneliness is a risk factor for increase rates of mortality (Luo *et al.*, 2012), while self-stigma negatively impacts on quality of life of people with mental health problems (Valiente *et al.*, 2015).

Another key outcome of this study is the development of a new theoretical model that explains loneliness, self-stigma, and culture through a multi-method approach by considering key aspects. The new model advances our academic knowledge because it conceptualises the relationships of self-stigma and loneliness, while highlights the significant role of culture and socio-demographic characteristics. Specifically the model explains the relationships between the concepts, highlights the role of emotional and social loneliness, indicates the role of collectivism in relation to emotional loneliness, and reveals the important role of insight into mental illness on the conceptualisation of self-stigma. The model advances our theoretical understandings of loneliness and self-stigma, provides useful theoretical information to future researchers, and gives them the opportunity to build on existing empirical evidence. Also the new model provides new dimensions for future research on the inter-relationships of loneliness, self-stigma and culture, while provides significant aspects to be considered by policy makers in relation to older adults with mental health problems in nursing homes.

Finally this study, through its findings, and the new theoretical model with its novice theoretical dimensions that reveal a new theoretical pathway of examining and understanding loneliness and self-stigma, highlight the need for future policies that specifically targeting the needs of older adults in nursing home. As discussed in chapters 8 and 10 existing policies in the UK overall fail to address the tremendous effects of emotional loneliness among this population. For example, the White Paper '*Caring for our future: reforming care and support*' (2012) although acknowledges the potential risks of loneliness among older adults in long-term care facilities, its strategies are targeting to eliminate social isolation. According to this study's findings, however, loneliness and particularly emotional loneliness, was found to be experienced by the majority of the residents. This shows that the quality of the relationships is important for this population, and in some cases even more determined than the quantity of their relationships.

In relation to mental illness stigma, policies and strategies target at reducing public stigma by failing to adequately report, tackle, and potentially eliminate self-stigma. An example for this is the '*Time to change*' UK's national campaign against mental illness stigma. The campaign focuses solely to public stigma by ignoring the severe effects of self-stigma in mentally ill's lives. It is also worth noting that no UK stigma policy exclusively refers to older adults experiencing mental health problems in long-term care facilities. However policies and strategies have been formed in relation to dementia among this population. These policies although significant for older adults' mental health well-being, they underestimate the severe effects of other types of mental illness among this population. This may result to worsen mental health well-being, and thus higher levels and of course increase experiences of self-stigma among them. The latter is highlighted by this study's findings that self-stigma is present among this population. As discussed across sections 11.1.1 and 11.1.2 (and thoroughly explained in chapters 8 and 10) this study provides both methodological and theoretical implications. These implications highlight how much important is to study, and potentially address the needs of this population. There is an urgent need towards this direction given the rapid growth of the ageing population which inevitably changes the form of UK's society.

11.2 Critical evaluation of the study

One of the main limitations of the study concerns its external validity. The sample size of this study is not representative of the target population. Therefore the findings cannot be

generalised, and should be viewed with caution. Methodological challenges impacted negatively on sampling procedures, and thus the sample size required for the study has not been met. However, the study provides a number of methodological lessons which can help and potentially improve future research in these (nursing homes) settings. In addition, setting a confidence interval as wide as 7.5 during the quantitative phase can also be considered a limitation in this study. As explained in section 7.2.5.1 a wider confidence interval results to higher estimated error that as a consequence jeopardises external validity.

The small sample size in the quantitative phase might not have effectively influenced the qualitative phase of this study. It may have even misled the direction of the qualitative phase given the small and under-powered sample of the quantitative phase, and, consequently, its lack of external validity. Setting a wider confidence interval and recruiting a small sample during the quantitative phase could have therefore jeopardised the overall implementation and justification of the qualitative phase particularly if the issues of self-stigma and loneliness were not identified. Therefore future researchers whom reasonably expect to find it difficult to obtain a statistically powered sample might wish to implement a qualitative study first so to inform the implementation of a quantitative design. The utilisation of a sequential mixed-method design, however, allowed the identification of eligible participants during the qualitative phase, and therefore provided important insights into the experiences of loneliness and self-stigma. As it was explained in Section 7.2.5.1 a wider confidence interval was set because of practical issues regarding sample recruitment (lack of resources). It is important, however, to highlight that the implementation of the qualitative phase of this study had an overall positive impact since it provided significant information and insights into loneliness and self-stigma.

Another limitation of this study relates to the analysis of the quantitative data. The low amount of data collected did not allow for more sophisticated statistical analysis (e.g. modelling) to be conducted. This resulted in the inability of identifying and potentially establishing relationships and associations between variables (e.g. individualism/collectivism and loneliness). Also, this problem did not allow within-cultural variations on self-stigma and loneliness to be statistically examined. However, the qualitative findings provided useful insight in this respect by revealing how emotional loneliness relates to cultural values.

The new theoretical model of loneliness and self-stigma was a key outcome of this study. The model was based on the findings of both phases of this study and not only the findings of the

qualitative phase. The qualitative findings to some extent, however, were prioritised over the quantitative results in explaining the relationships between the concepts (which could be perceived as a limitation). This resulted because of the concerns over statistical power and because it was not feasible to examine many of the variables quantitatively.

In addition, this study did not examine variations on experiences and levels of loneliness and self-stigma based on the geographical area participants were living in. However, studies examining loneliness have been previously identified variations on levels of loneliness among rural and urban areas. The same variations might also exist between rural and urban UK-based nursing homes.

The sample size challenges during the qualitative phase of this study may have also jeopardised the overall exploration of the phenomena. However, the researcher modified this phase's eligibility criteria so that to maximise participation rates. This resulted in the better exploration of the phenomena, and particularly the exploration of experiences of loneliness where theoretical saturation was achieved.

Older adults' experiences of self-stigma might have not been adequately explored. This is because the majority of older adults participated had no insight into their condition which might have jeopardised the adequate exploration of the phenomenon. Also, theoretical saturation in relation to self-stigma has not been achieved because of the limited number of participants who had insight into their illness and explicitly talked about their experiences of self-stigma. However, adequate inferences can be made in relation to understandings and views towards mental illness. Overall, the qualitative phase of this study provides an integrated picture of the concepts under exploration, while it provided an in depth understanding of older adults' experiences of loneliness and views about mental illness.

Finally, the researcher used unique ID numbers (no names), pseudonymous, and unique identifiers when direct quotes were used in order to increase the likelihood of participants and nursing homes anonymity. Also the researcher blinded any obvious clues in the quotes themselves that could potentially reveal participants' identity, and consequently nursing home's identity. However, the researcher cannot with complete certainty guarantee that anonymity did indeed occur in all instances. That is, despite all of the researcher's attempted measures in preventing such a circumstance from occurring, a staff member or someone how is connected to the home may potentially recognise the participant, and therefore the nursing

home he/she resides in. It is worth mentioning, however, that all ethical aspects related to the implementation of this study were taken into highly consideration, and the best practices were followed to maximise likelihood of participants' anonymity.

11.2.1 Evaluation of the effectiveness of the developed recruitment protocol

The adopted recruitment protocol was based on a 'multi-method' approach (see section 7.6.3.1.4). The approach involved non-monetary incentives, establishment of relationships of trust through face-to-face visits, and the involvement of people with previous personal contact and experience with nursing home providers. This section discusses the effectiveness of the adapted recruitment protocol by evaluating and reflecting upon the results of nursing homes recruitment.

The administration of non-monetary incentives was an effective method in maximising nursing homes recruitment since it increased the overall nursing homes response rates. The non-monetary incentives involved certificates of participation to both nursing homes provided access, and staff members completing the LTCF assessments. Also, the name of the nursing homes provided access would be included in the acknowledgement section of published articles, while during meetings the researcher offered biscuits and fruit juice to staff members attended. The nursing home managers were informed about the non-monetary incentives in the meeting with the researcher. However, participation rates still remained low (6 nursing homes participated in the study). Nursing home managers seemed interested in the incentives the researcher had to offer, yet they were not willing to provide access. Overall, the non-monetary incentives were not sufficient in motivate nursing home managers, and thus boost participation. This comes in line with previous findings. For example, Singer *et al.*, (1999) in a meta-analysis of 39 studies using incentives found that incentives are overall effective in studies with initial low response rates, yet monetary incentives are more effective in boosting participation compared to non-monetary ones (cited in Börsch-Supan *et al.*, 2013). Therefore it is possible that monetary incentives might have had a stronger impact on the recruitment of nursing homes.

Face-to-face visits in establishing relationships of trust with nursing home providers were also an effective approach. It is worth mentioning that the researcher through this recruitment approach scheduled 11 meetings with nursing home providers. The effectiveness of this approach has already been acknowledged from previous research studies in these settings.

For example, Elkins *et al.* (2011) argued that face-to-face communication was a key contributing strategy to hospitals, and nursing homes recruitment during a large project assessing facility-specific methods of collecting and reporting acquisition and infection rates due to highly antibiotic-resistant bacteria, in California. However, this approach was costly both in terms of time and finance. Lack of a personal vehicle and the long distances between eligible nursing homes made face-to-face visits often problematic and difficult. The researcher however physically visited all the eligible nursing homes, while nursing homes with large capacity were physically visited more than once. This was an additional practice adopted by the researcher in maximising the effectiveness of nursing homes recruitment, and thus the overall effectiveness of nursing homes recruitment protocol.

Finally, the involvement of people with previous experience and personal contact with nursing homes providers was another proposed key facilitator in increasing recruitment. The approach has already been followed (Milligan *et al.*, 2014), and tested (Asch *et al.*, 2000; Hanson *et al.*, 2010) in these settings. In this study, the University's links and prior contacts with nursing homes in Bedfordshire would be used. In other words, the researcher's intention was to use the Department of Healthcare Practice links with nursing homes due to researcher's lack of previous contact and/or personal experience with nursing providers in Bedfordshire. The researcher e-mailed key staff members of the Department of Healthcare Practice. The researcher in the e-mail introduced herself and her role in the University, provided key information about the study and kindly requested a meeting. However, the response was not effective. The researcher tried to re-contact the Department via phone calls. The researcher managed to talk to a key staff member from the Department. However, the support was still ineffective. The researcher did not manage to use the Department's links which might negatively affect the effectiveness of this study's recruitment protocol.

In order to overcome this, the ENRICH research network was contacted. The ENRICH research network facilitates recruitment in care homes through a network with 'ready to research homes'. The researcher through an e-mail provided key information about the study and asked them to support her with nursing homes recruitment. However, the network mainly supports recruitment in studies which are included in the NIHR Clinical Research Network Portfolio. This study was not included in the NIHR Clinical Research Network Portfolio, since it is a study in part of fulfilment of the degree of Doctor to Philosophy. However the network was happy to bring the researcher in touch with interested research care homes. The correspondence with the network, although effective in the beginning, was slow. The data

collection period had finished before the network being able to bring the researcher in touch with interested research care homes. Also, the correspondence was somehow inadequate because although the network was happy to talk over the phone with the researcher and provide guidance, this never really happened. The researcher called the person in charge four times and she never called the researcher back. Hanson *et al.*, (2010) argue that the recruitment and retention process of the nursing homes relied mainly on the investigators' previous personal contact with the nursing home providers. In this study, the lack of researcher's personal contact along with deficits in facilitating recruitment through the University's links, and later on with the ENRICH network links, were key influencing factors in the overall effectiveness of the adapted nursing homes recruitment protocol.

To sum, the recruitment protocol was overall adequate, yet several key factors influenced its overall effectiveness. Incentives were found to boost nursing homes recruitment but not sufficiently enough for the study to meet statistical power. Monetary incentives might have however increased participation rates, and thus maximised the nursing homes recruitment protocol. Face-to-face visits were highly effective despite being time consuming and expensive. Appropriate existing contacts with nursing homes providers, despite a well-established approach in recruiting nursing homes, proved problematic. These findings provide important methodological lessons and implications for future researchers (chapter 11, section 11.1).

11.3 Recommendations

The findings of the Phase 1 revealed the various methodological challenges in nursing homes research. This highlighted the need to meet these methodological challenges through the implementation of effective approaches that will allow researchers to conduct more rigorous research in these settings. In the UK, the ENRICH network provides support in advancing and enabling research within these settings. However, the network mainly provides support to studies which are included in the NIHR Clinical Research Network Portfolio. The latter is a potential barrier to a number of studies that could potentially increase our knowledge about the needs of this population (older adults in nursing homes). The need for establishing similar to ENRICH networks is therefore clear and immediate. The networks could facilitate and potentially increase long term care facilities participation in research studies which is significant. The more research is taking place in these settings, the more changes in

increasing our knowledge and developing effective policies that meet the needs of this population.

The findings come in line with previous findings in the loneliness literature. That is, older adults in nursing homes experience loneliness. Here the findings highlight that the quality of the intimate relationships is more important than the quantity. It is significant therefore, to develop a strong relationship between the residents and staff members so that to improve intimacy relationships among them. It would also be of a great value to develop and establish a volunteer network that would aim at providing emotional support to long term care facilities residents by, for example, every day visits. Another strategy to tackle loneliness among this population is to construct villages suitable for older adults similar to Hogewey in Netherlands. Hogewey is an experimental new village for older adults with severe dementia. The village provides a 24-hour care to the residents. The village also provides other facilities such as grocery, cafe, coffee shop, restaurant and even a beauty salon and barber shop. One important aspect of Hogewey village is that it provides to its residents the opportunity to enjoy their everyday activities. Hogewey's facilities are constructed to fit residents' backgrounds. Each house reflects a different style that is familiar to older adults who live in the house (The Gurdian, 2012) based on their societal and/or religion backgrounds. This is important given the findings of this study that cultural values, and religiousness are key in relation to loneliness. Germany and Switzerland have already announced they are planning to build similar villages (Archer, 2012), yet to come in the UK. Hogewey is a pioneering village that is effective and quite promising to change long-term care residents' lives.

Loneliness literacy is important among the staff and family members of residents. For example, staff members and family members should be aware of the causes and the debilitating effects of loneliness to older adults' mental and physical well-being (e.g. higher risk for cardiovascular diseases, dementia, and suicide ideation). Doing this, staff members could develop a number of within nursing homes policies that target at eliminating experiences of loneliness among older adults. Family members could also find ways of being close to long term care family members. One way is to send their own videos to their loved ones. Residents would not feel disconnected and/or unwanted from their families, which could potentially eliminate feelings of loneliness. Another possible way is the online social networking services. Nursing homes could provide training and support to older adults on how to use online social networking services. Older adults, therefore, would be able to

communicate with loved ones and/or to establish new social relationships that could serve as protective factors against experiences of loneliness.

Significant also is the cultural subscriptions of the residents. Staff members should acknowledge older adults priorities in life (e.g. family) which might intensify their experiences of loneliness. On the other hand, family members could develop a 'family visitors network'. That is, to plan every day visits to the nursing homes, and attend every day events so that residents to feel emotionally integrated.

Finally, the findings highlight the negative impact of sharing the same accommodation with severely mentally ill people to older adults' psychological well-being. Emotional instability, fear and reluctance to participate in common activities were key effects. Older adults who suffer from less severe forms of mental illness seem intolerant to residents who cannot maintain control because of their illness. Long-term care facilities need to potentially restructure the way are currently functioning. One possible recommendation towards this direction is to provide different activities depending on the residents' needs and functional ability. Another solution is to provide sufficient support to older adults who become aggressive, and/or lose control towards the other residents. The services provided by the long term care facilities should be specific and individually oriented.

11.4 Future research

This study has identified a number of key issues towards our understanding of levels and experiences of loneliness and self-stigma among mentally ill older adults residing in nursing homes. Future research should aim at providing rigorous findings in advancing our understandings regarding the phenomena among this population.

One of the key issues of this study relates to the methodological challenges, and particularly to the recruitment barriers in these settings. A number of scholars (e.g. Mody *et al.*, 2008; Davies *et al.*, 2014) have already highlighted the barriers and challenges of nursing homes recruitment in research studies. It would be of a great value, therefore, to explore the views and perceptions of staff members towards the implementation of research studies within their work environment, and evaluate their perspectives so that to inform and develop potentially more effective research designs. Also it would be valuable to systematically review previously implemented recruitment procedures in these settings, examine their effectiveness, and propose an effective method of nursing homes recruitment based on the lessons learnt

from previous studies. The latter is important with the increasing number of the ageing population (Department for Work and Pensions, 2015b), and thus people residing in long-term care facilities.

The methodological challenges resulted in a low amount of collected data. However, the findings indicated that older adults with mental health problems in nursing homes do become self-stigmatised. It would therefore be interesting to re-examine their levels of self-stigma by implementing a region-level cross-sectional study (East England). The latter would allow us to identify within-region (East England) self-stigma differences. It is also important to examine levels of self-stigma among older adults with mental health problems residing in other long-term care facilities such as residential care homes. This would help us to thoroughly understand whether and how older adults experience mental illness, and thus self-stigma. The latter is important given the increase number of older people experiencing mental health problems, and residing in long term care facilities.

The findings of the qualitative arm of this study indicated that older adults experience loneliness. It is important, therefore, to qualitatively explore older adults' experiences of loneliness at a national and/or regional level. This would allow us to identify any geographical differences that may exist, in the UK. The latter is of great value since the loneliness literature indicates differences in loneliness among rural/urban areas, yet our knowledge is limited in relation to older adults who reside in urban or rural UK-based nursing homes. By exploring and identifying these differences we will be able to develop specific policies that target at eliminating loneliness among this population.

Finally the findings resulted to the development of a new theoretical model which aims at explaining loneliness, stigma and culture among older adults with mental illness in nursing homes. Towards this direction, future research should be implemented in order to examine the aspects of the former theoretical model, and to explore whether or not these aspects explaining loneliness and stigma among this population. More specifically, it would be of a great value to explore how collectivism explains emotional loneliness among this group, and how emotional reactions relate to both forms of loneliness (social and emotional). Given the significant role of insight or no insight into illness in relation to stigma, it would be of a great value to explore further how and whether insight into one's illness relates to loneliness.

11.5 Conclusion

Through investigating the inter-relationships between self-stigma, loneliness and culture among older adults with mental health problems in nursing homes, the study has been able to investigate important psychosocial phenomena that have been underexplored over the years. This topic is particularly important considering the rapid growth of the ageing population in the UK, as well as the increasing number of older adults suffering from mental illness.

One important limitation of this study concerns the small sample size during the quantitative phase. Therefore, the findings of the quantitative phase should be viewed with caution, and should not be generalised to the target population. However, the study presented key findings for the sampled population which align with previously findings on the self-stigma and loneliness literature. That is, self-stigma and loneliness did exist among this population. More specifically, more than half of this study's participants reported low levels of self-stigma (56.3%), yet a substantial number of them scored high on the self-stigma scale (43.8%). More than half of the participants perceived themselves as sometimes lonely (68.8%), while 12.5% reported severe levels of loneliness. The qualitative findings indicated that insight into illness was important when experiencing self-stigma, yet loneliness was experienced by the majority of the participants. Marital status was key explanatory factor of levels of self-stigma, while age and religiousness were among the key factors explaining levels of loneliness. In addition, gender seemed to influence experiences of emotional loneliness among participants. The qualitative findings overall supported the quantitative results. Finally, the qualitative phase revealed that culture influences experiences of emotional loneliness among this population. However, because of the low data of the quantitative arm of this study no accurate inferences could be drawn about the statistical relationships between cultural values and levels of self-stigma and loneliness.

The new theoretical model, which was developed based on the findings of this study, offers a useful platform for future investigation of the concepts of loneliness, self-stigma and culture among the study population. The theoretical model highlights the key role of socio-demographic variables on the way loneliness and self-stigma is experienced, while highlights the key role of insight into illness in relation to experiences of self-stigma. Future studies could more systematically assess one's insight into illness in identifying in what extent and depth this factor may influence and/or explain experiences of self-stigma. As has been earlier argued, there are current indications of the relationship between insight into illness and self-

stigma, however a small number of studies examined whether and how insight into illness directly influences, explains and forms self-stigma attitudes. The theoretical model of this study therefore can shape future studies in this area since it highlights and stresses the need to both theoretically and empirically examine self-stigma and insight into mental illness. The theoretical model also reveals a potential relationship between attitudes and perceptions of mental health problems and possible behavioural reactions towards older adults with mental illness. It would of a great value to further explore how older adults with mental health problems in nursing homes view and perceive their fellow residents who also suffer from mental health problems, how their perceptions relate to specific behavioural reactions such as fear and avoidance, and how they inter-relate with loneliness. This is important given the findings of this study that older adults with less severe mental illness were reluctant to take part in activities when older adults who were perceived to have more severe forms of mental illness were also participating. Therefore, older adults with less severe forms of mental illness might be more likely to stigmatise mental health problems, withdraw themselves from social activities as a result, and potentially further experience loneliness.

In addition, the model acknowledges the significant role of both emotional and social loneliness, and particularly the key role of cultural values on experiences of emotional loneliness. Future studies may therefore wish to examine how differentiations of cultural values at the individual level explain and/or influence experiences of loneliness. The theoretical model also revealed a potential relationship between social and emotional loneliness and various emotional reactions such as sadness, desired isolation, and hostility. It would be of a great value therefore to further explore how social and emotional loneliness influence, relate and/or impact upon the emotional state of older adults with mental health problems in nursing homes. Another important future research based on the theoretical model of this study is how older adults in nursing homes cope with loneliness, and whether the adopted coping mechanisms are effective enough to combat loneliness. Finally, the model highlights the potential theoretical inter-relationship between loneliness and self-stigma. This inter-relationship may result through perceptions of inferiority, alienation, and feelings for social withdrawal. It is therefore important to further examine these relationships in order to identify whether self-stigma directly associates to loneliness, or associate to other factors, such as alienation and social withdraw (two important aspects of self-stigma) that serve as mediators between loneliness and self-stigma.

A significant outcome of this study relates to the methodological challenges faced during its implementation. More specifically, the barriers and challenges to nursing homes recruitment was a key methodological impact. Although the methodological challenges, the study provided significant insights into older adults' perceptions towards mental illness, loneliness, and cultural subscription. Another significant impact of this study was the theoretical model which was developed based on the findings of both phases. The model aimed at explaining loneliness, and stigma among this population, while it provided the framework for advancing, and potentially, re-capturing how loneliness, stigma and culture are experienced by older adults with mental health problems in nursing homes. As stated earlier the low size of the quantitative arm left no room for findings' generalisation, yet it provided the platform for further investigation on the topic.

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Appendix 1: The interRai-LTCF screening tool (Phase 1)

interRAI Long-Term Care Facility (LTCF)©

To be completed on behalf of residents

Instructions

The interRAI LTCF tool is a widely used, reliable and validated assessment tool which has been designed to be used by health care professionals on behalf of care home residents. The tool should be completed based on health care professionals' knowledge, opinion and personal observations of the residents. Where your review could benefit from additional information (e.g. review of the person's clinical records, discussion with other colleagues or/and the person him/herself) feel free to do so. The form consists of four sections: a) background information, b) cognition, c) communication, d) mood and behaviour. The assessments are only aiming to assess older adults' cognitive and psychological well-being. This study has ethical approval from the University of Bedfordshire and full approval from your institution.

Please read the following instructions that will help you to complete the assessment tool:

1. Work through one section at the time.
2. The assessments are not a test of your knowledge. Please reply based on your opinion.
3. Draw only on your existing knowledge, opinion and observation of this individual (additional information could be obtained).
4. Each statement is consisted of codes that are given on the form. Enter the appropriate codes on the form.
5. An assessment needs to be completed for each current resident.
6. Complete all the sections on the form.

SECTION A. RESIDENT BACKGROUND INFORMATION**1. Name of nursing home**

2. Name of resident (please enter first initials)

3. Gender

1. Male

2. Female

☐
4. Birthday

Day

Month

Year

5. Marital Status

1. Never Married

2. Married

3. Partner/Significant other

4. Widowed

5. Separated

6. Divorced

☐
6. Spoken Language

1. English

2. Other

☐
7. Mental Health*Record indicates history of mental illness*

0. NO

1. Yes

☐
SECTION B. COGNITION**1. Cognitive skills for daily decision making**
☐
*Making decisions regarding tasks of daily life—e.g. when to get up or have meals, which clothes to wear or activities to do*0. **Independent** – Decisions consistent, reasonable and safe1. **Modified Independence** – Some difficulty in new situations only2. **Minimally impaired**— In specific recurring situations, decisions become poor or unsafe; supervisions necessary at those times3. **Moderately impaired**—Decisions consistently poor or unsafe; supervision required at all times4. **Severely impaired**— Never or rarely makes decisions5. **No discernable consciousness, coma****2. Memory recall ability***Code for recall of what was learned or know*

0. Yes, memory OK

1. Memory problem

a. **Short-term memory OK**—Seems/appears to recall after 5 minutes ☐b. **Long-term memory OK**—Seems/appears able to recall distant past ☐c. **Procedural memory OK**—Can perform all or almost all steps in a multitask sequence without cues ☐d. **Situational memory OK**—Both: recognises ☐

caregivers' names/faces frequently encountered AND knows locations of places regularly visited (bedroom, dining room, activity room, therapy room)

3. Periodic Disordered thinking or awareness

0. Behaviour not present

1. Behaviour present, consistent with usual functioning

2. Behaviour present, appears different from usual functioning (e.g. new onset or worsening; different from a few weeks ago or first day of admission)

a. **Easily distracted**—e.g. episodes of difficulty paying attention; gets sidetracked ☐b. **Episodes of disorganised speech**—e.g., speech is nonsensical, irrelevant, or rambling from subject to subject; loses train of thought ☐c. **Mental function varies over the course of the day**—e.g., sometimes better, sometimes worse ☐**4. Acute change in mental status from person's usual functioning**

—e.g., restlessness, lethargy, difficult to arouse, altered environmental perception

0. NO

1. Yes

☐
5. Change in decision making as completed to 90 days ago or since first day of admission

0. Improved

2. Decline

1. No change

8. Uncertain

☐

SECTION C. COMMUNICATION

1. Making self understood (Expression) ☐

Expressing information content—both verbal and non-verbal

0. **Understood**—Expresses ideas without difficulty
1. **Usually understood**—Difficulty finding words or finishing BUT if given time, little or no prompting required
2. **Often understood**—Difficulty finding words or finishing thoughts AND prompting usually required
3. **Sometimes understood**—Ability is limited to making concrete requests
4. **Rarely or never understood**

2. Ability to understand others (Comprehension) ☐

0. **Understands**—Clear comprehension
1. **Usually understands**—Misses some part/intent of message BUT comprehends most conversation
2. **Often understands**—Misses some part/intent of message BUT with repetition or explanation can often comprehend conversation
3. **Sometimes understands**—Responds adequately to simple, direct communication only
4. **Rarely understands**

SECTION D. MOOD AND BEHAVIOUR

1. Indicators of possible depressed, anxious, or sad mood

Code for indicators observed, irrespective of the assumed cause

[Note: whenever possible ask person]

0. Not present
1. Present but not exhibited in last 3 days
2. Exhibited on 1-2 of last 3 days
3. Exhibited daily in last 3 days

a. **Made negative statements**—e.g., “nothing matters; Would rather be dead; What’s the use; Regret having lived so long; Let me die” ☐

b. **Persistent anger with self or other**—e.g., easily annoyed, anger at care received ☐

c. **Expressions, including non-verbal, of what appear to be unrealistic fears**—e.g., fear of being abandoned, being left alone, being with others; intense fear of specific objects or situations ☐

d. **Repetitive health complaints**—e.g., persistently seeks medical attention, incessant concern with body functions ☐

e. **Repetitive anxious complaints/concerns (non-health related)**—e.g., persistently seeks attention/reassurance regarding schedules, meals, laundry, clothing, relationships ☐

f. **Sad, pained, or worried facial expressions**—e.g., furrowed brow, constant frowning ☐

g. **Crying, tearfulness** ☐

h. **Recurrent statements that something terrible is about to happen**—e.g., believes he or she is about to die, have a heart attack ☐

i. **Withdrawal from activities of interest**—e.g., long standing activities, being with family/friends ☐

j. **Reduced social interactions** ☐

k. **Expressions, including non-verbal, of a lack of pleasure in life**—e.g., “I don’t enjoy anything anymore” ☐

2. Self-reported mood

0. Not in last 3 days
1. Not in last 3 days, but often feels that way
2. In 1-2 of last 3 days
3. Daily in the last 3 days
8. Person could not respond

Ask: “In the last 3 days, how often have you felt....”

a. **Little interest or pleasure in things you normally enjoy?** ☐

b. **Anxious, restless, or uneasy?** ☐

c. **Sad, depressed, or hopeless?** ☐

3. Behaviour Symptoms

Code for indicators observed, irrespective of the assumed cause

0. Not present
1. Present but not exhibited in last 3 days
2. Exhibited on 1-2 of last 3 days
3. Exhibited daily in last 3 days

a. **Wandering**—Moved with no rational purpose, seemingly obvious to needs or safety ☐

b. **Verbal abuse**—e.g., others were threatened, screamed at, cursed at

☐

c. **Physical abuse**—e.g., others were hit, shoved, scratched

☐

d. **Socially inappropriate or disruptive behaviour**—e.g., made disruptive sounds or noises, screamed out, smeared or threw food or faces, hoarded, rummaged through other's belongings

☐

e. **Inappropriate public sexual behaviour or public disrobing**

☐

f. **Resists care**—e.g., taking medications/injections, ADL assistance, eating

☐

Appendix 2: Quantitative questionnaire tool during pilot study (Phase 1)

Questionnaire

Name of nursing home:

Date of birth:

SECTION A - Background information

1. How old are you? _____

2. What is your sex?

Male ☐

Female ☐

3. What is your first language? (please specify)

4. What is your ethnic group? (please specify)

5. What is your highest educational level?

Primary school ☐

Secondary School ☐

College ☐

Undergraduate ☐

Postgraduate

☐ Other _____ (please specify)

6. What is your marital status?

Single ☐

Married ☐

Divorced/Separated ☐

Widowed ☐

7. What was your occupation previous to retirement?

_____ (please specify)

8. How religious do you perceive yourself to be?

Extremely religious ☐ Quite religious ☐ Not very religious ☐ Atheist/Agnostic ☐
 Other _____ (please state)

9. How long have you been living in the nursing home?

_____ (please specify)

SECTION B – The following consists of a list of statements. Please, indicate the response that you **most** agree with. Have you recently:

10. Been able to concentrate on whatever you are doing.	Better than usual	Same as usual	Less than usual	Much less than usual
11. Been able to face up your problems.	More so than usual	Same as usual	Less able than usual	Much less able
12. Felt constantly under strain.	Not at all	No more than usual	Rather more than usual	Much more than usual
13. Lost much sleep over worry.	Not at all	No more than usual	Rather more than usual	Much more than usual
14. Felt capable of making decisions about things.	More so than usual	Same as usual	Less so than usual	Much less capable
15. Been feeling unhappy and depressed.	Not at all	No more than usual	Rather more than usual	Much more than usual
16. Felt that you are playing a useful part in things.	More so than usual	Same as usual	Less useful than usual	Much less useful
17. Been losing confidence in yourself.	Not at all	No more than usual	Rather more than usual	Much more than usual
18. Felt you couldn't overcome your difficulties.	Not at all	No more than usual	Rather more than usual	Much more than usual
19. Been thinking of yourself as a worthless	Not at all	No more than	Rather more	Much more than

person.		usual	than usual	usual
20. Been feeling reasonably happy all things considered.	More so than usual	About the same as usual	Less so than usual	Much less than usual
21. Been able to enjoy your normal day to day activities.	More so than usual	Same as usual	Less so than usual	Much less than usual

SECTION C – The following consists of a list of statements. Please, indicate the response that expresses you the **most**.

22. I feel out of place in the world because I have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
23. I am disappointed in myself for having a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
24. People without mental illness could not possibly understand me.	Strongly Agree	Agree	Disagree	Strongly Disagree
25. Having a mental illness has spoiled my life.	Strongly Agree	Agree	Disagree	Strongly Disagree
26. I am embarrassed or ashamed that I have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
27. I feel inferior to others who do not have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
28. Because I have a mental illness, I need others to make most decisions for me.	Strongly Agree	Agree	Disagree	Strongly Disagree
29. Stereotypes about the mentally ill apply to me.	Strongly Agree	Agree	Disagree	Strongly Disagree
30. Mentally ill people tend to be violent.	Strongly Agree	Agree	Disagree	Strongly Disagree
31. People with mental illness cannot live a good, rewarding life.	Strongly Agree	Agree	Disagree	Strongly Disagree
32. I can't contribute anything to society because I have a mental	Strongly Agree	Agree	Disagree	Strongly

illness.				Disagree
33. Mentally ill people should not get married.	Strongly Agree	Agree	Disagree	Strongly Disagree
34. People can tell that I have a mental illness by the way I look.	Strongly Agree	Agree	Disagree	Strongly Disagree
35. People ignore me or take me less seriously just because I have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
36. Nobody would be interested in getting close to me because I have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
37. People often patronize me, or treat me like a child, just because I have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
38. Others think that I can't achieve much in life because I have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
39. People discriminate against me because I have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
40. I stay away from social situations in order to protect my family or friends from embarrassment.	Strongly Agree	Agree	Disagree	Strongly Disagree
41. I don't talk about myself much because I don't want to burden others with my mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
42. Being around people who don't have a mental illness makes me feel out of place or inadequate.	Strongly Agree	Agree	Disagree	Strongly Disagree
43. I don't socialize as much as I used to because my mental illness might make me look or behave "weird".	Strongly Agree	Agree	Disagree	Strongly Disagree
44. Negative stereotypes about mental illness keep me isolated from the "normal" world.	Strongly Agree	Agree	Disagree	Strongly Disagree

Strongly Agree

55. I usually sacrifice my self-interest for the benefit of my group

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

Strongly Agree

56. I often do 'my own thing'

1	2	3		4	5	6		7	8	9
---	---	---	--	---	---	---	--	---	---	---

Strongly Agree

57. I feel good when I cooperate with others

1 2 3 4 5 6 7 8 9_

Strongly Agree

58. Children should feel honoured if their parents receive a distinguished award

1 2 3 4 5 6 7 8 9

Strongly Agree

59. I am a unique individual

1	2	3		4	5	6		7	8	9
---	---	---	--	---	---	---	--	---	---	---

Strongly Agree

60. Without competition it is not possible to have a good society

1 2 3 4 5 6 7 8 9

Strongly Agree

61. I would do what would please my family, even if I detested the activity

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

62. I enjoy working in situations involving competition with others

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

63. The well-being of my co-workers is important to me

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

64. I would sacrifice an activity that I enjoy very much if my family did not approve of it

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

65. If a co-worker gets a prize I would feel proud

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

66. How lonely do you perceive yourself to be?

Always lonely ☐ Often lonely ☐ Sometimes lonely ☐ Never lonely ☐

In order to deeply explore how culture influences feelings of loneliness and self-stigma among older adults living in nursing homes, I aim to conduct a series of one-to-one interviews in the near future. The interviews will last approximately 45 minutes. The participation in the interview is in a voluntary basis and you can withdraw at any time. If you are willing to take part in the interview, I will write down your name and your details on a separate sheet so that your identification can be kept securely.

Would you be interested in participating in an interview?

Yes ☐

No ☐

**THANK YOU FOR YOUR PARTICIPATION
IN THIS STUDY. YOUR CONTRIBUTION IS
GREATLY APPRECIATED.**

Appendix 3: Participant information sheet (pilot study Phase 1)

PARTICIPANT INFORMATION SHEET

My name is Vasiliki Tzouvara. I am a research student from the University of Bedfordshire (Institute for Health Research). My study explores the relationships of feelings of loneliness, and views about mental health problems and culture among older adults in nursing homes.

Invitation

I would like to invite you to take part in this research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take as much time as you need to read the following information carefully and discuss it with others if you wish. Please feel free to ask me or my supervisors if there is anything that is not clear or if you would need more information on the subject. Take as much time that you need to decide whether or not you wish to take part.

Why have I been chosen?

We would like to invite you to participate in this research study if you are someone who is aged 65 or over and reside in a nursing home. This would make you eligible for this study.

What is the purpose of the research study?

The purpose of this study is to understand loneliness, views about mental illness and culture among older adults residing in nursing homes. I am also very interested in exploring if and how culture affects feelings of loneliness and views about mental illness among older adults in nursing homes. I am interested in these areas because of their importance and also because of the small amount of research dealing with these issues.

Do I have to take part?

It is completely your decision whether to participate or not in this study. If you decide to participate in this research study, please read and sign the 'informed consent form' below and then complete the questionnaire. If you decide to participate but would prefer to withdraw after you have begun completing the questionnaire, you may do so at any time without needing to provide a reason. A decision to withdraw will not affect you in any way. If this happens, the data you have entered up to the point will not be saved or used in this research study.

What do I have to do?

Please read very carefully the information below. The most important thing that we would request from you is to answer all of the questions truthfully. You should also be aware that there are no right or wrong answers, as this questionnaire is not a test. At the end of the questionnaire, you will see an invitation to take part in an audio-recorded interview at an appropriate time and place in the nursing home. This interview will explore the issues of culture, loneliness and mental health in more detail. If you wish to express an interest in participating in this interview, please write your name on the separate sheet on the last page of this form. Please do not write your name on the questionnaire.

Will my taking part in this study be kept confidential?

All of information collected during this research study will be kept strictly confidential. No names and no information that allows us to identify you will be collected. All of the data will be stored in compliance with the UK Data Protection Act 1998 and will be securely saved using a password that only my supervisors and I will have access to. This study has obtained ethical clearance by the Institute for Health Research Ethics Committee.

What will happen to the results of the study?

The information collected will be analysed and written up within my PhD thesis which will be freely available to access at the University of Bedfordshire's library. The findings of this study will be used to educate health professionals about the extent and way that loneliness, perceptions about mental illness and culture affect older adults in nursing homes. It is also my intention to publish this work in mental health journals so that the findings and recommendations we make are read about within the mental health community.

If you have any questions please feel free to contact either me or my supervisors. Our contacts are below.

IMPORTANT CONTACT INFORMATION

My name: Vasiliki Tzouvara, University of Bedfordshire, Putteridge Bury Campus, Hitchin Road, Luton, Bedfordshire, LU2 8LE. Telephone number: 01582-743115. **E-mail:** vasiliki.tzouvara@beds.ac.uk

My supervisor: Dr. Chris Papadopoulos, University of Bedfordshire, Putteridge Bury Campus, Room 32, Hitchin Road, Luton, Bedfordshire, LU2 8LE. **E-mail:** chris.papadopoulos@beds.ac.uk

Appendix 4: Informed consent form (pilot study Phase 1)

INFORMED CONSENT FORM

TITLE OF STUDY: Understanding loneliness and perceptions about mental illness among older adults from different cultures

Please tick these boxes to confirm your informed consent:

1. I confirm that the researcher has read the participant information sheet to me and have had the opportunity to ask questions ☐
2. I confirm that I have understood the information have been provided to me via the participant information sheet ☐
3. I understand that taking part in the research is voluntary and that I am free to withdraw at any time without giving any reason ☐
4. I understand that any information I will provide will be treated with complete confidence ☐
5. I understand that this study has received ethical approval from the Institute for Health Research Ethics Committee and that all ethical issues will be strictly adhered to ☐

.....

Participant Initials

Signature

Date

.....

Name of Researcher

Signature

Date

Appendix 5: Ethics approval letter of pilot study (Phase 1)



22 October 2013

Vasiliki Tzouvara
Student number: 1118392

Dear Vasiliki Tzouvara

Re: IHREC Application No: IHREC263

Project Title: Self-stigma and loneliness among older adults with mental health problems residing in nursing homes: An individualistic – collectivistic approach

The Ethics Committee of the Institute for Health Research has considered your revised application for ethical approval and has decided that the proposed research project should be approved.

Please note that if it becomes necessary to make any substantive change to the research design, the sampling approach or the data collection methods a further application will be required.

Yours sincerely



Dr Yannis Pappas
Head of PhD School, Institute for Health Research
Chair of Institute for Health Research Ethics Committee

Appendix 6: Formal invitation letter (Phase 1)



Institute for Health Research
Putteridge Bury
Hitchin Road, Luton
Beds LU2 8LE

Vasiliki Tzouvara
PhD Research Student
tel: 01582 743 115
mob: 07456 138 008
email: vasiliki.tzouvara@beds.ac.uk,
Supervisor email: chris.papadopoulos@beds.ac.uk

Date X, XXXX

[Name of nursing home]

[Address]

[Name of nursing home manager],

My name is Vasiliki Tzouvara and I am a doctoral student at the University of Bedfordshire (Institute for Health Research). I am undertaking a research study that aims to explore the potential inter-relationships between mental illness self-stigma, loneliness and culture among older adults with mental health problems residing in nursing homes. This study is one of several being undertaken by the University of Bedfordshire in co-operation with care and nursing homes in England.

With this letter, I would like to ask you to meet with me at a time convenient for you so that I can explain the nature of the research and the study's procedures. I would like to assure you that residents will not be subject to harm or stress and that participation in this study is absolutely voluntary. Participants can withdraw from the study at any time without giving a reason. All collected data will be treated with complete confidentiality and participant anonymity will be assured. No information regarding the nursing home will be disclosed or obtained, as this study focuses only on the residents' views on culture, self-stigma and loneliness.

The results will produce significant knowledge for the healthcare sector. There is already substantive research evidence that highlights the range of negative outcomes among people who self-stigmatised

their own mental health problems. However, we know very little about this issue, including its prevalence and manifestation, among older adults with mental health problems. It is likely that people who self-stigmatise are at a greater risk of experiencing loneliness (which itself is a powerful moderator of health outcomes) but we do not as yet have evidence that supports (or rejects) this relationship. By also understanding the role that culture plays upon the relationship of self-stigma and loneliness, we will be in a future position to form evidence-based culturally sensitive and tailored interventions aimed at reducing self-stigma and its effects, including loneliness.

In the envelope, I have also enclosed the ethical approval letter, which has been obtained by the Ethics Committee of the Institute for Health Research at the University of Bedfordshire.

I very much hope that you would be happy to set up a meeting to discuss this study and the possibility of sampling your nursing home residents. To do so, please email me at vasiliki.tzouvara@beds.ac.uk or contact me by telephone (07456 138 008).

Thank you very much for taking the time to read this letter. I very much hope to hear from you soon.

Yours Sincerely,

Vasiliki Tzouvara

Appendix 7: Questionnaire tool main study (Phase 1)

Questionnaire

Name of nursing home:

Date of birth:

SECTION A - Background information

1. How old are you? _____

2. What is your sex?

Male ☐ Female ☐

3. What is your first language? (please specify)

4. What is your ethnic group?

White-British ☐ Black-British ☐ Asian-British ☐ Black ☐ Asian ☐ White other ☐

5. What is your highest educational level?

Primary school ☐ Secondary School ☐ College ☐ Undergraduate ☐ Postgraduate ☐
Other _____ (please specify)

6. What is your marital status?

Single ☐ Married ☐ Divorced/Separated ☐ Widowed ☐

7. What was your occupation previous to retirement?

_____ (please specify)

8. How religious do you perceive yourself to be?

Extremely religious ☐ Quite religious ☐ Not very religious ☐ Atheist/Agnostic ☐
Other _____ (please state)

9. How long have you been living in the nursing home?

_____ (please specify)

SECTION B – The following consists of a list of statements. Please, indicate the response that you **most** agree with. **Have you recently:**

10. Been able to concentrate on whatever you are doing.	Better than usual	Same as usual	Less than usual	Much less than usual
11. Been able to face up your problems.	More so than usual	Same as usual	Less able than usual	Much less able
12. Felt constantly under strain.	Not at all	No more than usual	Rather more than usual	Much more than usual
13. Lost much sleep over worry.	Not at all	No more than usual	Rather more than usual	Much more than usual
14. Felt capable of making decisions about things.	More so than usual	Same as usual	Less so than usual	Much less capable
15. Been feeling unhappy and depressed.	Not at all	No more than usual	Rather more than usual	Much more than usual
16. Felt that you are playing a useful part in things.	More so than usual	Same as usual	Less useful than usual	Much less useful
17. Been losing confidence in	Not at all	No more than	Rather more	Much more than

yourself.		usual	than usual	usual
18. Felt you couldn't overcome your difficulties.	Not at all	No more than usual	Rather more than usual	Much more than usual
19. Been thinking of yourself as a worthless person.	Not at all	No more than usual	Rather more than usual	Much more than usual
20. Been feeling reasonably happy all things considered.	More so than usual	About the same as usual	Less so than usual	Much less than usual
21. Been able to enjoy your normal day to day activities.	More so than usual	Same as usual	Less so than usual	Much less than usual

SECTION C – The following consists of a list of statements regarding your perceptions about mental illness. Please, indicate the response that you agree the **most**.

22. I feel out of place in the world because I have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
23. I am disappointed in myself for having a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
24. People without mental illness could not possibly understand me.	Strongly Agree	Agree	Disagree	Strongly Disagree
25. Having a mental illness has spoiled my life.	Strongly Agree	Agree	Disagree	Strongly Disagree
26. I am embarrassed or ashamed that I have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree

27. I feel inferior to others who do not have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
28. Because I have a mental illness, I need others to make most decisions for me.	Strongly Agree	Agree	Disagree	Strongly Disagree
29. Stereotypes about the mentally ill apply to me.	Strongly Agree	Agree	Disagree	Strongly Disagree
30. Mentally ill people tend to be violent.	Strongly Agree	Agree	Disagree	Strongly Disagree
31. People with mental illness cannot live a good, rewarding life.	Strongly Agree	Agree	Disagree	Strongly Disagree
32. I can't contribute anything to society because I have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
33. Mentally ill people should not get married.	Strongly Agree	Agree	Disagree	Strongly Disagree
34. People can tell that I have a mental illness by the way I look.	Strongly Agree	Agree	Disagree	Strongly Disagree
35. People ignore me or take me less seriously just because I have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
36. Nobody would be interested in getting close to me because I have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree

37. People often patronize me, or treat me like a child, just because I have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
38. Others think that I can't achieve much in life because I have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
39. People discriminate against me because I have a mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
40. I stay away from social situations in order to protect my family or friends from embarrassment.	Strongly Agree	Agree	Disagree	Strongly Disagree
41. I don't talk about myself much because I don't want to burden others with my mental illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
42. Being around people who don't have a mental illness makes me feel out of place or inadequate.	Strongly Agree	Agree	Disagree	Strongly Disagree
43. I don't socialize as much as I used to because my mental illness might make me look or behave "weird".	Strongly Agree	Agree	Disagree	Strongly Disagree
44. Negative stereotypes about mental illness keep me isolated from the	Strongly Agree	Agree	Disagree	Strongly Disagree

53. Competition is the law of nature

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

54. My happiness depends very much on the happiness of those around me

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

55. I usually sacrifice my self-interest for the benefit of my group

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

56. I often do 'my own thing'

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

57. I feel good when I cooperate with others

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

58. Children should feel honoured if their parents receive a distinguished award

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

59. I am a unique individual

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

60. Without competition it is not possible to have a good society

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

61. I would do what would please my family, even if I detested the activity

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

62. I enjoy working in situations involving competition with others

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

63. The well-being of my co-workers is important to me

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

64. I would sacrifice an activity that I enjoy very much if my family did not approve of it

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

65. If a co-worker gets a prize I would feel proud

1	2	3	4	5	6	7	8	9
Strongly Disagree			Unsure			Strongly Agree		

66. How lonely do you perceive yourself to be?

Always lonely ☐ Often lonely ☐ Sometimes lonely ☐ Never lonely ☐

In order to deeply explore how culture influences feelings of loneliness and self-stigma among older adults living in nursing homes, I aim to conduct a series of one-to-one interviews in the near future. The interviews will last approximately 45 minutes. The participation in the interview is in a voluntary basis and you can withdraw at any time. If you are willing to take part in the interview, I will write down your name and your details on a separate sheet so that your identification can be kept securely.

Would you be interested in participating in an interview?

Yes ☐

No ☐

**THANK YOU FOR YOUR PARTICIPATION
IN THIS STUDY. YOUR CONTRIBUTION IS
GREATLY APPRECIATED.**

Appendix 8: Certificates of participation main study (Phase 1)

1. Certificate for staff members completed the screening tool



Self-stigma and loneliness among mentally ill older adults in nursing homes: an individualistic-collectivistic approach

Certificate of participation

This is to certify that the **Name of Staff Member** has kindly agreed to participate in this research study. This work is sponsored by the Institute for Health Research, in the University of Bedfordshire. The contribution of **Name of Staff Member** is greatly appreciated by IHR and the University of Bedfordshire.

Vasiliki Tzouvara. Date_____

Institute for Health Research

Dr. Chris Papadopoulos ,
Date_____

Prof. Gurch Randhawa

2. Certificate for nursing homes provided access



Self-stigma and loneliness among mentally ill older adults in nursing homes: an individualistic-collectivistic approach

Certificate of participation

This is to certify that the **Name of Nursing Home** has kindly agreed to participate in this research study. This work is sponsored by the Institute for Health Research, in the University of Bedfordshire. The contribution of **Name of Nursing Home** is greatly appreciated by IHR and the University of Bedfordshire.

Vasiliki Tzouvara. Date_____

Institute for Health Research

Dr. Chris Papadopoulos ,
Date_____

Prof. Gurch Randhawa

Appendix 9: Participant information sheet (main study Phase 1)

PARTICIPANT INFORMATION SHEET

My name is Vasiliki Tzouvara. I am a research student from the University of Bedfordshire (Institute for Health Research). My study explores the relationships of feelings of loneliness, and views about mental health problems and culture among older adults in nursing homes.

Invitation

I would like to invite you to take part in this research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take as much time as you need to read the following information carefully and discuss it with others if you wish. Please feel free to ask me or my supervisor if there is anything that is not clear or if you would need more information on the subject. Take as much time that you need to decide whether or not you wish to take part.

Why have I been chosen?

I would like to invite you to participate in this research study if you are someone who is aged 60 or over and reside in a nursing home. This would make you eligible for this study.

What is the purpose of the research study?

The purpose of this study is to understand older adults' views about mental illness, and their relationships with feelings of loneliness and culture. I am also very interested in exploring if and how culture affects feelings of loneliness and views about mental illness among older adults in nursing homes. I am interested in these areas because of their importance to older adults' well-being. This study is undertaken in fulfilment of the degree of Doctor to Philosophy.

Do I have to take part?

It is completely your decision whether to participate or not in this study. If you decide to participate in this research study, please read and sign the 'informed consent form' below and then complete the questionnaire. If you decide to participate but would prefer to withdraw after you have begun completing the questionnaire, you may do so at any time without needing to provide a reason. A decision to withdraw will not affect you in any way. If this happens, the data you have entered up to the point will not be saved or used in this research study.

What do I have to do?

Please read very carefully the information below. The most important thing that I would request from you is to answer all of the questions truthfully. You should also be aware that there are no right or wrong answers, as this questionnaire is not a test. At the end of the questionnaire, you will see an invitation to take part in an audio-recorded interview at an appropriate time and place in the nursing home. This interview will explore the issues of culture, loneliness and mental health in more detail. If you wish to express an interest in participating in this interview, please write your date of birth and the name of the nursing home on the separate sheet on the last page of this form. Please do not write your name on the questionnaire.

Will my taking part in this study be kept confidential?

All of information collected during this research study will be kept strictly confidential. No names and no information that allows us to identify you will be collected. All of the data will be stored in compliance with the UK Data Protection Act 1998 and will be securely saved in a computer using a password that only my supervisors and I will have access to. This study has obtained ethical clearance by the Institute for Health Research Ethics Committee.

What will happen to the results of the study?

The information collected will be analysed and written up within my PhD thesis which will be freely available to access at the University of Bedfordshire's library. The findings of this study will be used to educate health professionals about the extent and way that loneliness, perceptions about mental illness and culture affect older adults in nursing homes. It is also my intention to publish this work in mental health journals so that the findings and recommendations we make are read about within the mental health community.

How the results will be disseminated to the participants?

Older adults who participated and want to, can ask the researcher to give them a copy of the published articles. Also, my intention is to make the findings of this study known to older adults through newsletters.

If you have any questions please feel free to contact either me or my supervisors. Our contacts are below.

IMPORTANT CONTACT INFORMATION

My name: Vasiliki Tzouvara, University of Bedfordshire, Putteridge Bury Campus, Hitchin Road, Luton, Bedfordshire, LU2 8LE. Telephone number: 01582-743115. **E-mail:** vasiliki.tzouvara@beds.ac.uk

My supervisor: Dr. Chris Papadopoulos, University of Bedfordshire, Putteridge Bury Campus, Room 32, Hitchin Road, Luton, Bedfordshire, LU2 8LE. **E-mail:** chris.papadopoulos@beds.ac.uk

Appendix 10: Informed consent form (main study Phase 1)

INFORMED CONSENT FORM

TITLE OF STUDY: Understanding loneliness and perceptions about mental illness among older adults.

Please tick these boxes to confirm your informed consent

1. I confirm that the researcher has read the participant information sheet to me and have had the opportunity to ask questions ☐

Or I confirm that I have read the participant information and have had the opportunity to ask questions ☐

2. I confirm that I have understood the information have been provided to me via the participant information sheet ☐

3. I understand that taking part in the research is voluntary and that I am free to withdraw at any time without giving any reason ☐

4. I understand that any information I will provide will be treated with complete confidence ☐

5. I understand that this study has received ethical approval from the Institute for Health Research Ethics Committee and that all ethical issues will be strictly adhered to ☐

.....

Participant Initials

Signature

Date

.....

Name of Researcher

Signature

Date

Appendix 11: Information sheet of “interest expression” in Phase 2

Participants	Date of Birth	Nursing home
1.		
2.		
3.		
4.		
5.		

Appendix 12: Ethics approval letter (main study/Phase 1)



23rd April 2014

Vasiliki Tzouvara
Student number: 1118392

Dear Vasiliki Tzouvara

Re: IHREC Application No: IHREC263 (Revised)
Project Title: Self-stigma and loneliness among mentally ill older adults in nursing homes: an individualistic-collectivistic approach

The Ethics Committee of the Institute for Health Research has considered your revised application for ethical approval and has decided that the proposed research project should be approved.

Please note that if it becomes necessary to make any substantive change to the research design, the sampling approach or the data collection methods a further application will be required.

Yours sincerely



Dr Yannis Pappas
Head of PhD School, Institute for Health Research
Chair of Institute for Health Research Ethics Committee

Appendix 13: Initial eligibility criteria of Phase 2

Participants eligibility criteria:

Inclusion Criteria

- Older adults over 60 years old and older.
- Any genders.
- Older adults who have been identified to have mental health problems through the screening tool (first phase).
- Older adults who possess the cognitive ability to participate in the study.
- Older adults residing in nursing homes in the origin of Bedfordshire.
- Older adults who speak and understand the English language.
- Older adults who participated in the questionnaire survey (first phase)
- Older adults who expressed an interest to participate in the qualitative interviews
- Older adults who have been found to subscribe in individualistic and/or collectivistic cultural values through the quantitative phase (first phase).

Exclusion Criteria

- Older adults younger than 60 years old.
- Community dwelling older adults.
- Older adults who have not been identified to have mental health problems through the screening tool (first phase).
- Older adults who do not possess the cognitive abilities to participate (such as end stage Alzheimer or other degenerative disorders psychosis, or severe forms of aphasia).
- Older adults who do not understand and speak the English language.
- Older adults who did not participate in the questionnaire survey (first phase).
- Older adults who did not express an interest to participate in the qualitative interviews.
- Older adults who have not been identified to subscribe in individualistic and/or collectivistic cultural values through the quantitative phase (first phase).

Appendix 14: Initial interview guide (Phase 2)

Interview Schedule

Self-stigma and loneliness among older adults with mental health problems residing in nursing homes: an individualistic-collectivistic approach

Introduction

- Thank the participant for agreeing to participate.
- Introduce myself, role, and research aims.
 - I am a research student in the University of Bedfordshire.
 - This study is aiming to explore the views about mental illness, and loneliness
 - To gain an understanding of experiences of feelings of loneliness and views of mental illness among older adults
 - This study is funded by the University of Bedfordshire
- Briefly explain what you will discuss during the interview
 - We will discuss about feelings of loneliness and views about mental illness.
- Explaining the interviewing process
 - The discussion will last approximately less than one and a half hour.
 - Ethical considerations, anonymity, confidentiality of the data, audio recording.
 - Ensure the participant that he/she will go no under stress and make clear that he/she can withdraw at any given time and without stating the reason why.
- Ask the participant if he/she has any questions regarding the process.
- Take informed consent by distributing the participant information sheet and informed consent form.
 - Ask the participant about his/her background information (date of birth, age, ethnic group, time of residence in the nursing home)

I. Cultural Values (Individualism-Collectivism)

The following questions and probe questions (when and if it is necessary) will be used in order older adults' cultural values to be explored.

1. Could you please tell me a bit about your life before coming in the nursing home? (*Explore self: living arrangements, stay alone or with family members, never leave family environment, work environment*)
2. Could you please tell me a bit about yourself now? (*Explore self/priorities: Family vs self, career vs family, successful at work, would you sacrifice your personal achievements for the sake of your family? Why? Why not?*)
3. How close do you think families should be? (*Explore family relationships: How often should families see each other? How near should they live to each other?*)
4. Can you talk to me about your family? (*Explore family relationships: Tell me about the relationships you have had with your family? tight, close relationships with family? Get together often?*)
5. In life what is important and worthwhile to you? (*Explore understanding of personal values and norms: for example family harmony, family should be united, family should stay together, children should take care of their parents when they get old, success, money, Why are these important to you? What the most important values are for you?*)

II. Mental illness self-stigma

The following questions and probe questions (when and if it is necessary) will be used in order self-stigma in association to older adults' cultural orientation to be explored.

1. What does poor mental health mean to you? (*Explore their understanding of the condition: could you give me some examples?*)
2. What do others think about older adults who have poor mental health? (*Explore if they are aware of the stereotypes towards mental illness: do you think that others view older adults who have often sad mood and behaviour differently? If yes, how? Do they view them negatively/positively? Why do you say that?*)
3. How do you personally view older adults with poor mental health? (*Explore stereotype agreement: do you view them differently, unworthy, inferior? If yes, how? What kind of thoughts do you have when you think about older adults with poor mental health?*)
4. Do you think that you have sometimes poor mental health? (*If yes, how do you experience it? How would you describe your experience?*)(*If no, what makes you feel happy?*)
5. How does that make you feel about yourself? (*Explore stereotype application: Does this make you feel bad, sad, unworthy, isolated, burden to your family? Why do you feel that way? Do you talk to others about it (having poor mental health), If yes, how do you describe yourself? If no, Why?*).

III. Loneliness

The following questions and probe questions (when and if it is necessary) will be used in order feelings of loneliness in association to older adults' cultural orientation to be explored.

1. How would you describe your life in this nursing home? *(Explore feelings about his life in the nursing home, boring/routine, easy going/strictness, much to do, quality, safety, therapy)*
2. How did you feel when you first moved here? *(Explore feelings about his experience of relocation, do you still feel this way today/now? How do you feel about being away from your previous environment? Why do you feel this way?)*
3. Do you often take part in any activities taking place in the nursing home? *(Explore social engagement, If yes, do you enjoy them? What activities do you do here? If no, why?)*
4. How are your relationships with the other residents here like? *(Explore emotional loneliness: close, good, feel attached to someone)*
5. Do you have someone here that you could talk about very personal things with? *(Explore emotional loneliness: if yes how you would describe your relationship with him/her? If no, would you like to be able to talk with somebody about personal things? If yes why? If no why not?)*
6. Do you have family or friends that visit you *(if yes how often? How does it make you feel?)*
7. Do you sometimes feel lonely here? *(Explore experiences of loneliness: if yes when do you feel lonely and why? if not, Why do you think that is?)*

IV. Closing Question

1. Do you want to add something last regarding what we have discussed until now?

Closing

- Thank the participant about their contribution
- Remind that their responses will be treated with confidentiality

Appendix 15: Participant information sheet (Phase 2)

PARTICIPANT INFORMATION SHEET

My name is Vasiliki Tzouvara. I am a research student from the University of Bedfordshire (Institute for Health Research). My study explores the relationships of feelings of loneliness, and views about mental health problems and culture among older adults in nursing homes.

Invitation

I would like to invite you to take part in this research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take as much time as you need to read the following information carefully and discuss it with others if you wish. Please feel free to ask me or my supervisor if there is anything that is not clear or if you would need more information on the subject. Take as much time that you need to decide whether or not you wish to take part.

Why have I been chosen?

I would like to invite you to participate in this research study if you are someone **who is aged 60 or over**, reside in a nursing home and expressed an interest to participate in the interviews. This would make you eligible for this study.

What is the purpose of the research study?

The purpose of this study is to understand older adults' views about mental illness, and their relationships with feelings of loneliness and culture. I am also very interested in exploring if and how culture affects feelings of loneliness and views about mental illness among older adults in nursing homes. I am interested in these areas because of their importance to older adults' well-being. This study is undertaken in fulfilment of the degree of Doctor to Philosophy.

Do I have to take part?

It is completely your decision whether to participate or not in this study. If you decide to participate in this research study, please read and sign the 'informed consent form' below. If you decide to participate but would prefer to withdraw after you have begun the interview, you may do so at any time without needing to provide a reason. A decision to withdraw will not affect you in any way. If this happens, the data collected up to the point will be destroyed and will not be used in this research study.

What do I have to do?

Please read very carefully the information below. The most important thing that I would request from you is to answer the questions truthfully. You should also be aware that there are no right or wrong answers. The interview will take place in a convenient time for you in the nursing home and it is anticipated to last approximately one hour. The interviews will be audio-recorded and transcribed by me. Once the interviews will be transcribed, the audio recordings will be then destroyed.

Will my taking part in this study be kept confidential?

All of information collected during this research study will be kept strictly confidential. No names will be collected and false names (pseudonyms) will be used. This will ensure your anonymity and that the information which has been collected cannot be traced back to you. All of the data will be stored in compliance with the UK Data Protection Act 1998 and will be securely saved in a computer using a password that only my supervisors and I will have access to. This study has obtained ethical clearance by the Institute for Health Research Ethics Committee.

What will happen to the results of the study?

The information collected will be analysed and written up within my PhD thesis which will be freely available to access at the University of Bedfordshire's library. The findings of this study will be used to educate health professionals about the extent and way that loneliness, perceptions about mental illness and culture affect older adults in nursing homes. It is also my intention to publish this work in mental health journals so that the findings and recommendations we make are read about within the mental health community.

How the results will be disseminated to the participants?

Older adults who participated and want to, can ask the researcher to give them a copy of the published articles. Also, my intention is to make the findings of this study known to older adults through newsletters.

If you have any questions please feel free to contact either me or my supervisors. Our contacts are below.

IMPORTANT CONTACT INFORMATION

My name: Vasiliki Tzouvara, University of Bedfordshire, Putteridge Bury Campus, Hitchin Road, Luton, Bedfordshire, LU2 8LE. Telephone number: 01582-743115. **E-mail:** vasiliki.tzouvara@beds.ac.uk

My supervisor: Dr. Chris Papadopoulos, University of Bedfordshire, Putteridge Bury Campus, Room 32, Hitchin Road, Luton, Bedfordshire, LU2 8LE. **E-mail:** chris.papadopoulos@beds.ac.uk

Appendix 16: Informed consent form (Phase 2)

INFORMED CONSENT FORM

TITLE OF STUDY: Understanding loneliness and perceptions about mental illness among older adults.

Please tick these boxes to confirm your informed consent

1. I confirm that the researcher has read the participant information sheet to me and have had the opportunity to ask questions ☐

Or I confirm that I have read the participant information sheet and have had the opportunity to ask questions ☐

2. I confirm that I have understood the information have been provided to me via the participant information sheet ☐

3. I understand that taking part in the research is voluntary and that I am free to withdraw at any time without giving any reason ☐

4. I understand that any information I will provide will be treated with complete confidence ☐

5. I understand that this study has received ethical approval from the Institute for Health Research Ethics Committee and that all ethical issues will be strictly adhered to ☐

.....

Participant Initials

Signature

Date

.....

Name of Researcher

Signature

Date

Appendix 17 Ethics approval letter for pilot study (Phase 2)



14 August 2014

Vasiliki Tzouvara
Student number: 1118392

Dear Vasiliki Tzouvara

Re: IHREC Application IHREC406

Project Title: Self-stigma and loneliness among older adults with mental health problems residing in nursing homes: An individualistic – collectivistic approach

The Ethics Committee of the Institute for Health Research has considered your application and has decided that the proposed research project should be approved with no amendments.

Please note that if it becomes necessary to make any substantive change to the research design, the sampling approach or the data collection methods a further application will be required.

Yours sincerely

A handwritten signature in blue ink, appearing to read "Yannis Pappas".

Dr Yannis Pappas
Head of PhD School, Institute for Health Research
Chair of Institute for Health Research Ethics Committee

Appendix 18: Revised interview guide (main study/Phase 2)

Interview Schedule

Self-stigma and loneliness among older adults with mental health problems residing in nursing homes: an individualistic-collectivistic approach

Introduction

- Thank the participant for agreeing to participate.
- Introduce myself, role, and research aims.
 - I am a research student in the University of Bedfordshire.
 - This study is aiming to explore the views about mental illness, and loneliness
 - To gain an understanding of experiences of feelings of loneliness and views of mental illness among older adults
 - This study is funded by the University of Bedfordshire
- Briefly explain what you will discuss during the interview
 - We will discuss about feelings of loneliness and views about mental illness.
- Explaining the interviewing process
 - The discussion will last approximately less than one and a half hour.
 - Ethical considerations, anonymity, confidentiality of the data, audio recording.
 - Ensure the participant that he/she will go no under stress and make clear that he/she can withdraw at any given time and without stating the reason why.
- Ask the participant if he/she has any questions regarding the process.
- Take informed consent by distributing the participant information sheet and informed consent form.
 - Ask the participant about his/her background information (date of birth, age, ethnic group, time of residence in the nursing home)
 -

I. Cultural Values (Individualism-Collectivism)

The following questions and probe questions (when and if it is necessary) will be used in order older adults' cultural values to be explored.

1. Could you please tell me a bit about your life before coming in the nursing home? (*Explore self: living arrangements, stay alone or with family members, never leave family environment, work environment*)

2. How would you describe yourself/personality? (*Explore self/priorities: How would your friends describe you? Could you please talk to me about yourself? Family vs self, career vs family, successful at work, would you sacrifice your personal achievements for the sake of your family? Why? Why not?*)
3. How close do you think families should be? (*Explore family relationships: How often should families see each other? How near should they live to each other?*)
4. Can you talk to me about your family? (*Explore family relationships: Tell me about the relationships you have had with your family? tight, close relationships with family? Get together often?*)
5. In life what is important and worthwhile to you? (*Explore understanding of personal values and norms: for example family harmony, family should be united, family should stay together, children should take care of their parents when they get old, success, money, Why are these important to you? What the most important values are for you?*)

II. Mental illness self-stigma

The following questions and probe questions (when and if it is necessary) will be used in order self-stigma in association to older adults' cultural orientation to be explored.

1. What does mental illness mean to you? (*Explore their understanding of the condition: What does poor mental health mean to you? could you give me some examples?*)
2. What do people in the community think about older adults with mental illness? (*Explore if they are aware of the stereotypes towards mental illness: do you think that people in the community view older adults who have often sad mood and behaviour differently? If yes, how? Do they view them negatively/positively? Why do you say that?*)
3. How do you personally view older adults with mental illness? (*Explore stereotype agreement: do you view them differently, unworthy, inferior? If yes, how? What kind of thoughts do you have when you think about older adults with poor mental health?*)
4. Do you think that you have sometimes poor mental health? (*If yes, how do you experience it? How would you describe your experience?*)(*If no, what makes you feel happy?*)
5. How does that make you feel about yourself? (*Explore stereotype application: Does this make you feel bad, sad, unworthy, isolated, burden to your family? Why do you feel that way? Do you talk to others about it (having poor mental health), If yes, how do you describe yourself? If no, Why?*)

III. Loneliness

The following questions and probe questions (when and if it is necessary) will be used in order feelings of loneliness in association to older adults' cultural orientation to be explored.

1. How would you describe your life in this nursing home? (*Explore feelings about his life in the nursing home, boring/routine, easy going/strictness, much to do, quality, safety, therapy*)
2. How did you feel when you first moved here? (*Explore feelings about his experience of relocation, do you still feel this way today/now? How do you feel about being away from your previous environment? Why do you feel this way?*)
3. Do you often take part in any activities taking place in the nursing home? (*Explore social engagement, If yes, do you enjoy them? What activities do you do here? If no, why?*)
4. How are your relationships with the other residents here like? (*Explore emotional loneliness: close, good, feel attached to someone*)
5. Do you have someone here that you could talk about very personal things with? (*Explore emotional loneliness: if yes how you would describe your relationship with him/her? If no, would you like to be able to talk with somebody about personal things? If yes why? If no why not?*)
6. Do you have family or friends that visit you (*if yes how often? How does it make you feel?*)
7. Do you sometimes feel lonely here? (*Explore experiences of loneliness: if yes when do you feel lonely and why? if not, Why do you think that is?*)

IV. Closing Question

1. Do you want to add something last regarding what we have discussed until now?

Closing

- Thank the interviewee about his/her participation
- Remind that their responses will be treated with confidentiality

Appendix 19: Ethics approval letter for main study (Phase 2)



7 December 2014

Vasiliki Tzouvara

Student number: 1118392

Dear Vasiliki Tzouvara

Re: IHREC Application No: IHREC441 (Revised)

Project Title: Self-stigma and loneliness among mentally ill older adults in nursing homes: an individualistic-collectivistic approach

The Ethics Committee of the Institute for Health Research has considered your revised application for ethical approval and has decided that the proposed research project should be approved.

Please note that if it becomes necessary to make any substantive change to the research design, the sampling approach or the data collection methods a further application will be required.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'Yannis Pappas'.

Dr Yannis Pappas

Head of PhD School, Institute for Health Research
Chair of Institute for Health Research Ethics Committee

A narrative review of the theoretical foundations of loneliness

Vasiliki Tzouvara, Chris Papadopoulos, Gurch Randhawa

Vasiliki Tzouvara, PhD Student, Chris Papadopoulos, Senior Lecturer, Gurch Randhawa, Professor of Diversity in Public Health and Director, All at Institute for Health Research, University of Bedfordshire, England

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Loneliness is a subjective feeling that can be debilitating, frightening, and undesirable, particularly when it leads to poor health. This is reflected by Killeen (1998:763) who argues that loneliness:

'[I]s a very destructive condition and it can cause a vicious downward spiral because the more lonely one becomes the more one is isolated even further from 'normal' society, and without care one can "go under".'

Loneliness and the notion of feeling alone is a universal feeling inherently linked with the notion of being human (Karnick, 2005). The prevalence of loneliness has been evidenced across a wide range of populations. For example, Victor and Yang (2012), using data from the European Social Survey, examined levels of loneliness across age groups (15+ years) in a UK sample of 2393 participants. They found that 6% of the adult population was severely lonely, while comparisons between age groups revealed that those aged under 25 years and those aged above 65 years had the highest levels of loneliness (9%). Nicolaisen and Thorsen (2014) also examined differences on the prevalence of loneliness across age groups (18–81 years) in a large Norwegian general population sample (n=14 743). The study examined data from the Norwegian LOGG (Life Course, Generation, and Gender) study and assessed levels of loneliness by using two different loneliness measures: the de Jong Gierveld Loneliness Scale and a single-item loneliness question. The findings revealed that levels of loneliness were high across the population, with both measures indicating very similar prevalence (24% and 21%, respectively).

Other studies have reported significant findings on cross-national variations on prevalence of loneliness. For example, Yang and Victor (2011) examined European Social Survey data to analyse the prevalence of loneliness across different age groups between 25 European countries (n=47 099). The findings revealed that although levels of loneliness increase with age, clear differences across nationalities also exist. Russia and Eastern European nations reported the highest prevalence of loneliness (almost 10%–34% across age groups) and Northern European nations the lowest (mostly below 6%). Such variation

indicates the importance of social and cultural influences in experiencing feelings of loneliness.

Loneliness has also been found to be a key risk factor in a range of negative health outcomes, including morbidity (Victor et al, 2005) and mortality (Luo et al, 2012; Holwerda et al, 2012; Newall et al, 2013; Steptoe et al, 2013). For example, in their 26-year longitudinal cohort birth study of 1034 children, Caspi et al (2006) found that loneliness was significantly associated with higher cardiovascular health risks (coefficient of determination (R^2)=1.37, 95% confidence interval (CI)=1.17–1.61). The relationship remained significant even when other previously well-established risk factors for poor health were controlled (e.g. low childhood socioeconomic status, IQ, and weight) (R^2 =1.34, 95% CI=1.10–1.64). Thurston and Kubzansky (2009), using data from the First National Health and Nutrition Examination Survey (US), report similar findings. The authors sampled 3003 community-dwelling individuals to examine associations between loneliness and incidents of coronary heart disease. After controlling for age, race, education, income, marital status, hypertension, diabetes, cholesterol, physical activity, smoking, alcohol use, systolic and diastolic blood pressures, body mass index, and depressive symptoms, high levels of loneliness remained significantly associated with higher risk of coronary heart disease incidence among women (hazard ratio=1.76, 95% CI=1.17–2.63).

ABSTRACT

Loneliness has been found to relate to a wide range of harmful health outcomes. The adverse effects of loneliness upon people's lives emphasise the importance of understanding its nature and process. A number of theoretical and conceptual foundations have been proposed by scholars and are discussed and reflected upon in this article. The discussion and understanding of loneliness theoretical foundations provide useful insights toward the interpretation of its occurrence.

KEY WORDS

Loneliness, Social support, Existentialism, Psychodynamic analysis
Cognitive therapy

Appendix 21: Accepted article for publications with ‘Nurse Researcher’

Title

Challenges and barriers to nursing homes recruitment: Lessons learned from a quantitative cross-sectional pilot study.

Authors

Vasiliki, Tzouvara, Chris, Papadopoulos, Gurch Randhawa

Abstract

The aging population is growing rapidly. With a growing older adult population comes an increase in admission rates to long-term care facilities such as nursing homes, and residential care homes. Assisted health care services should be flexible, integrated, and responsive to older adults' needs. However a limited body of empirical evidence exists because of the recruitment challenges in these settings. This paper describes the barriers and challenges of recruitment during a recent pilot study, considers previously implemented and proposed recruitment strategies, and proposes a new 'multi-method' approach towards the maximisation of care homes recruitment.